1

2 **Standardised Data on Initiatives – STARDIT:**

3 **Beta Version**

4 **Authors' information**

5 Corresponding author: Jack.Nunn@ScienceForAll.World

First name	Middle initial	Last names	Affiliation
Jack	S.	Nunn	Director of Science for All (Education Charity registered in Australia), Melbourne, Australia
			School of Public Health, La Trobe University, Victoria, Australia
Thomas		Shafee	School of Life Sciences, La Trobe University, Victoria, Australia
Steven		Chang	La Trobe University, Victoria, Australia
Richard		Stephens	Patient Advocate, Co-Editor-in-Chief, 'Research Involvement and Engagement'
Jim		Elliot	Public Involvement Lead at Health Research Authority (England)
Sandy		Oliver	Professor of Public Policy at UCL Institute of Education
Denny		John	Evidence Synthesis Specialist, Campbell South Asia, New Delhi, India
			Adjunct Assistant Professor, Amrita Institute of Medical Sciences & Research Centre, Kochi, Kerala, India
Maureen		Smith	Cochrane Consumer Executive Co-chair
Neil		Orr	Department of Linguistics, Faculty of Medicine, Health and Human Sciences, Macquarie University
			Poche Centre Indigenous Health, The University of Sydney
Jennifer		Preston	University of Liverpool
Josephine		Borthwick	University of Melbourne

Thijs		van Vlijmen	Taylor and Francis
James		Ansell	Consumers Health Forum of Australia
Francois		Houyez	European Organisation for Rare Diseases
Maria		Sharmila Alina de Sousa	Independent research and development consultant
Roan	D.	Plotz	Applied Ecology and Environmental Change Research Group, Institute for Sustainable Industries and Liveable Cities, Victoria University, Melbourne, Australia.
Jessica	L	Oliver	Australian Citizen Science Association
Yaela		Golumbic	University of Sydney
Rona		Macniven	The Poche Centre for Indigenous Health, Faculty of Medicine and Health, The University of Sydney, NSW 2006, Australia
			School of Population Health, Faculty of Medicine and Health, University of New South Wales, Sydney 2052, Australia;
			Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney 2109, Australia
Samuel		Wines	Co-Labs Melbourne
Ann		Borda	The University of Melbourne
			University College London
Håkon		da Silva Hyldmo	Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services
Pen-Yuan		Hsing	University of Bath, United Kingdom
			MammalWeb project
Lena		Denis	Johns Hopkins University
Carolyn		Thompson	Institute of Zoology, Zoological Society of London
			University College London

7 Plain English summary

8 All major problems, including complex global problems such as air pollution and pandemics, require
9 reliable data sharing between disciplines in order to respond effectively. Such problems require
10 evidence-informed collaborative methods, multidisciplinary research and interventions in which the
11 people who are affected are involved in every stage. However, there is currently no standardised way to
12 share information about initiatives and problem-solving across and between fields such as health,
13 environment, basic science, manufacturing, education, media and international development.

14 A multi-disciplinary international team of over 100 citizens, experts and data-users has been involved in
15 co-creating STARDIT to help everyone in the world share, find and understand information about
16 collective human actions, which are referred to as 'initiatives'.

17 STARDIT is an open access data-sharing system to standardise the way that information about initiatives
18 is reported, including information about which tasks were done by different people. Reports can be
19 updated at all stages, from planning to evaluation, and can report impacts in many languages, using
20 Wikidata. STARDIT is free to use, and data can be submitted by anyone. Report authors can be verified
21 to improve trust and transparency, and data checked for quality.

22 STARDIT can help create high-quality standardised information on initiatives trying to solve complex
23 multidisciplinary global problems. Among its main benefits, STARDIT offers those carrying out research
24 and interventions access to standardised information which enables well-founded comparisons of the
25 effectiveness of different methods. This article outlines progress to date; information about submitting
26 reports; planned next steps and how anyone can become involved.

27 Abstract

28 Background

29 There is currently no standardised way to share information across disciplines about initiatives,
30 including fields such as health, environment, basic science, manufacturing, media and international
31 development. All problems, including complex global problems such as air pollution and pandemics
32 require reliable data sharing between disciplines in order to respond effectively. Current reporting
33 methods also lack information about the ways in which different people are involved in initiatives,
34 making it difficult to collate and appraise data about the most effective ways to involve different
35 people.

36 Objective

37 STARDIT (**Standardised Data on Initiatives**) was created to help everyone in the world find and
38 understand information about collective human actions, which are referred to as 'initiatives'. STARDIT
39 enables multiple categories of data to be reported in a standardised way across disciplines, facilitating
40 appraisal of initiatives and aiding synthesis of evidence for the most effective ways for people to be
41 involved in initiatives.

42 Method

43 STARDIT is an open access web-based data-sharing system which standardises the way that information
44 about initiatives is reported across diverse fields and disciplines, including information about which
45 tasks were done by which stakeholders. STARDIT data is hosted using Wikidata; it works across multiple

46 languages and is both human and machine readable. Reports can be updated throughout the lifetime of
47 an initiative, from planning to evaluation, allowing anyone to be involved in reporting impacts and
48 outcomes.

49 STARDIT development is guided by participatory action research (PAR) paradigms, and has been co-
50 created with people from multiple disciplines around the world in multiple ways, working with
51 Indigenous people, cancer patients, health researchers, environmental researchers, economists,
52 librarians and academic publishers.

53 Results

54 Over 100 people from multiple disciplines have been involved in co-designing STARDIT. STARDIT reports
55 have been created for peer-reviewed research in multiple journals. A working Beta version was publicly
56 released in February 2021 ([ScienceforAll.World/STARDIT](https://scienceforall.world/stardit)).

57 Keywords

58 Data, open, standardised, participatory, democracy, evidence, systematic, genomics, health, indigenous

59

Introduction

Background

Many problems facing life on earth transcend the capacity of any single discipline to address. For example, problems such as pandemics, air pollution and biodiversity destruction cannot be characterised solely as ‘public health’, ‘environment’ or ‘education’ problems.(1,2) Solving such problems calls for holistic approaches(3) and will require governments, industry, research organisations and people around the world to work in partnership.

People need access to valid and reliable information to make informed decisions(4), which typically requires evidence. Depending on the context, this evidence-informed approach is called ‘research’, ‘evaluation’(5), ‘international development’, ‘education’ or an ‘initiative’. Hereafter all of the above will be referred to as ‘initiatives’. For example, when deciding a response to a pandemic, standardised data can improve retrieval of relevant information which can be used to inform which affected individuals or organisations could be involved in the design of the response and which outcomes are most important. This can include deciding which stakeholders should be involved in which tasks, such as prioritising outcomes.

In this article we explain how **Standardised Data on Initiatives (STARDIT)** builds on work to date by standardising a wide variety of data in a format applicable across multiple sectors, disciplines and languages. It is hoped that the creation of this evidence base will add to understanding and evaluating what works, for whom, why, and in what circumstances.(6–9). Hereafter, data generated by an initiative (including raw data), information about the data (meta-data) and information about the initiative will all be referred to as ‘data’ unless otherwise specified.

In 2020, the United Nations Secretary-General stated that *‘purposes that involve data and analytics permeate virtually all aspects of our work in development, peace and security, humanitarian, and human rights’*, encouraging *‘everyone, everywhere’* to *‘nurture data as a strategic asset for insight, impact and integrity – to better deliver on our mandates for people and planet’*(10). Similarly, the United Nation’s Paris Agreement highlighted the critical role of ‘sharing information, good practices, experiences and lessons’ in response to preventing irreversible climate change(11). While organisations such as Cochrane (health) and The Campbell Collaboration (social sciences) are working to create high-quality systematic reviews of medical, social and economic initiatives, there remain limitations to the data available for such reviews. After a recommendation from the Organisation for Economic Co-operation and Development (OECD), successful data sharing initiatives in biodiversity exist, such as the Global Biodiversity Information Facility (GBIF)(12), however there also remain limitations and accessibility issues in sharing and standardising biodiversity data(13,14).

It is often essential to include those affected by initiatives in the design and delivery of those initiatives(15). For example, with an initiative to respond to a pandemic, those creating and delivering an initiative, and those affected by the outcome may be the same people. Forms of participatory action research where anyone can be involved in any aspect of research (including amorphous terms such as ‘citizen science’) are increasingly recognised as crucial paradigms for solving such global problems such, as they can help ensure that initiatives are aligned with the priorities of those affected(16,17). However, while the importance of involving people is clear,(6) evidence-informed methods of doing so are lacking.(8,18–22)

1101 A recent statement defined a role for the public in ‘data intensive’ health research.(23) While in the
1102 health research disciplines there are over 60 different tools for reporting or supporting public
1103 involvement, most published tools are not used beyond the groups that developed them, and none
1104 work across multiple disciplines.(24) Current reporting methods also lack information about the ways in
1105 which different people are involved in initiatives, making it difficult to collate and appraise data about
1106 the most effective ways to involve different people. In addition, ‘citizen science’ and ‘participatory
1107 action research’ are blurring the lines between concepts such as ‘researcher’, ‘public’, ‘patient’ and
1108 ‘citizen’. (8,25–29)

1109 In addition to providing new standardised data categories for describing who was involved in which
1110 tasks of an initiative, STARDIT can also incorporate the many existing data standards (see the
1111 supplementary resources ‘Using Standardised Data on Initiatives (STARDIT): Beta Version Manual’), thus
1112 creating a unifying system for data hosting, linking and analysis. STARDIT can also report any different
1113 ‘interests’ of stakeholders and the ways power is shared between different stakeholders. The word
1114 ‘stakeholders’ here includes the public, those who have important knowledge, expertise or views that
1115 should be taken into account and others with a ‘stake’ in an initiative(30,31).

1116 Stakeholders can also include people who have financial, professional, social or personal ‘interests’. An
1117 ‘interest’ can include a kind of commitment, goal, obligation, duty or sense of connection which relates
1118 to a particular social role, practice, profession, experience or medical diagnosis and may (32). These can
1119 include financial or other interests which may compete or conflict with ‘public interest’.(33) For
1120 example, a systematic review found that industry funded research is more likely to have outcomes
1121 favouring those with financial interests who are sponsoring the research(33,34). Other examples include
1122 people from certain sub-populations (including those from populations more likely to be exploited(35)),
1123 Indigenous peoples, or people affected by rare diseases may have a personal interest in initiatives
1124 relevant to those specific populations, separate to the ‘general public’.(8,36–38) For example a person
1125 with a rare disease may have a personal ‘interest’ in research into a treatment for that disease(38).
1126 STARDIT allows standardised reporting of stakeholders and any interests.

1127 Sharing data in a consistent way may help ensure that benefits of initiatives are shared more equitably
1128 (for example, by improving accountability).(8) In addition sharing information about who ‘owns’ or
1129 controls access to data and how such data access decisions are made can help people make informed
1130 decisions about participating in research(38). By reporting involvement in initiatives, STARDIT also
1131 allows acknowledgement of people otherwise excluded from the public record – such as patients,
1132 people donating personal data, medical writers, laboratory assistants, citizen scientists collecting or
1133 analysing data, custodians of traditional or Indigenous knowledge, translators, interviewers, coders and
1134 code reviewers.

1135 Objective

1136 The objective of STARDIT is to address current limitations and inconsistencies in sharing data about
1137 initiatives. The STARDIT system features standardised data reporting about initiatives, including who has
1138 been involved, what tasks they did, and any impacts observed. STARDIT is designed to support a culture
1139 of partnership across disciplines and is, wherever possible, aligned and interoperable with existing
1140 reporting models and frameworks such as those used in health, environment, manufacturing ,
1141 publishing, government policy, education, arts and international development (see Table 1). In addition,
1142 the STARDIT Preference Mapping (STARDIT-PM) tool provides a standardised way to report information
1143 about different stakeholders’ preferences, including preferences for power-sharing and methods of
1144 involving people during an initiative. The working Beta Version of STARDIT uses Wikidata

(collaboratively edited structured data) to enable definitions to be co-created by contributors anywhere in the world, and therefore works across human languages, with interoperability with other platforms planned for future versions. A link to the working Beta version can be found at: ScienceforAll.World/STARDIT/Beta(39)

Current usage

The STARDIT provides a way to report data about who did which tasks in an initiative. STARDIT reports have also been used to describe a number of research projects, including data about who did which tasks, ethics approval, funding, methods and outcomes(37,40,41). In health research, projects which have used STARDIT reports include participatory action research projects involving a large cohort study of >15,000 healthy, elderly research participants(42), a protocol for precision medicine for Aboriginal Australians(43), and a group of patients and families affected by a rare immunological disorder(38), and a project involving extended family of donor-siblings who share the same sperm-donor father(37). An environmental research project has also used STARDIT to report the initiative, which works with citizen scientists to locate critically endangered species using eDNA(44,45). In medicine, STARDIT is already being used by the Wikipedia-integrated open access peer reviewed WikiJournals, which has articles which are integrated into Wikidpedia.(46) For example, a STARDIT report has been created to share information about a Wiki Journal of Medicine article about systematic reviews (with an associated integrated Wikipedia page)(47), including information about authors, editors and peer-reviewers(48). This allows readers to critically appraise the source before deciding whether to use or share it.

Potential applications

STARDIT's potential applications are summarised in Table 1. Among the principal applications, STARDIT offers public access to standardised information which enables the comparison of methods with the most impacts, such as ways of involving stakeholders in initiatives. The United Nations defines assessing impact as 'establishing cause and effect chains to show if an intervention has worked and, if so, how'.(49) With more data being shared, STARDIT could support decision making when planning stakeholder involvement in initiatives, and enable more people to assess the rigour of impact assessments.(49)

For example, many industries use self-regulatory processes to govern industry practices, with examples including the Forest Stewardship Council (FSC), Marine Stewardship Council (MSC)(50), Certified B Corporations,(51) and multiple Good Manufacturing Practice (GMP) guidelines. STARDIT could be used to improve public awareness of, and access to the data already reported by such self-regulatory standards. Increased transparency could, for example, support people to make informed decisions when investing or buying products; automate analysis of data to facilitate such decisions, and improve accountability overall.

In addition, STARDIT could be used to share information which makes research more reproducible(52,53), improving accessibility to the information required to critically appraise research and evidence and thus improving trust in processes such as the scientific method(54,55), and facilitate an appraisal of different knowledge systems, including Indigenous knowledge systems(56). Such data sharing could also improve the translation of trusted, quality research and data, by empowering people to both access and appraise relevant data. For example, improved access to more standardised information (in multiple languages) about data and outcomes, could help to facilitate more informed collaborations between researchers and those monitoring and protecting critically endangered species, particularly where there is no common language(57–59).

Defining ‘initiative’ and ‘involvement’

As STARDIT is designed to report data across disciplines, distinctions between concepts such as ‘intervention’, ‘research’, ‘project’, ‘policy’, ‘initiative’ (and similar terms) are of secondary importance compared with communicating ‘the aims or purposes of specified actions’; ‘who did which tasks or actions’; ‘are there competing or conflicting interests’, and the ‘outcomes from a specific action’. In this way, STARDIT can be used to report on any kind of collective action, which can include interventions, projects or initiative – including a clinical study, education interventions or any kind of evaluation^(5,60,61). In this article, we use the word ‘initiative’ to describe any intervention, research or planned project which is a kind of collective human action. We define ‘involving’ people as the process of carrying out research, initiatives or interventions with people, rather than on them.⁽⁶²⁾ Involvement occurs when power is shared by researchers, research participants, and other relevant stakeholders (such as the public, industry representatives and experts). While meanings of these terms are often imprecise and can be used interchangeably, ‘involvement’ here is distinct from ‘engagement’, which is where which information and knowledge about initiatives is shared, for example, with study participants who remain passive recipients of interventions^(63–65).

Using and developing data standards

The current Beta Version of STARDIT maps terms and concepts using the Wikidata initiative (part of the Wikimedia Foundation)³⁶, which includes definitions (taxonomy), a way of describing relationships between concepts (ontology)³⁷, and a system to translate definitions and ontology between many languages. Examples of existing taxonomies include the National Library of Medicine’s Medical Subject Headings (MeSH), which are used extensively in multiple kinds of literature reviews³⁸.

How to involve people in combining or merging overlapping taxonomies for different subsets of data has been identified as an important question in the process of taxonomy^(66,67). By using Wikidata, STARDIT can be used by anyone to store both publicly accessible data and metadata (data about data), and link to hosted structured linked data. While STARDIT is a novel element set, where possible it will also incorporate element sets from established data standards and map them where possible (see [Table 5](#) in appendix for examples of data standards which could be incorporated). This includes standard elements and value sets and controlled vocabularies⁽⁶⁸⁾. The terms used in this paper are working terms, which will be progressively standardised over the lifetime of the project.

Structured Wikidata can help define terms and concepts clearly and unambiguously, in a transparent and open way. For example, colours in the spectrum are described by a standard numerical code in Wikidata, whereas the names of colours change according to different languages. Also, people with different DNA variations will also experience some colours differently. Similarly, the Wikidata entry for ‘patient’ has the human-readable definition of ‘person who takes a medical treatment or is subject of a case study’ (translated into 54 other languages) and a machine-readable definition consisting of dozens of semantic links to and from other Wikidata entries³⁹. The terms ‘[participant](#)’ and ‘[research participant](#)’ are similarly coded, defined and translated. For terms that do not currently exist in Wikidata (for example, ‘biobank participant’), a definition can be contributed by anyone in any language, refined by other users, then coded and translated into multiple languages by Wikidata. Developing taxonomies and ontologies will be an ongoing process facilitated by the current Wikidata infrastructure, and may require creating additional tools to create more inclusive ways of involving people in developing taxonomies.⁴⁰

229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269

Methods and paradigms

Participatory action research

STARDIT development is guided by participatory action research (PAR) paradigms, which guides initiatives by aiming to involve all stakeholders in every aspect of the development and evaluation of an initiative(69,70). Participatory research is a form of collective, self-reflective enquiry undertaken by people in order to understand their situation from different perspectives(71). Development has also been influenced by existing work in health research, including the multidisciplinary area of public health, which incorporates social, environmental and economic research. In a health context, participatory research attempts to reduce health inequalities by supporting people to be involved in addressing health issues that are important to them, data collection, reflection and ultimately in action to improve their own health(72). At the core of participatory research is ‘critical reflexivity’. The process asks people involved to reflect on the causes of problems, possible solutions, take any actions required which might improve the current situation, and evaluate the actions(70).

Rights-based paradigm

The United Nations (UN) Universal Declaration Human Rights states everyone should be able to ‘receive and impart information and ideas’(73). The UN also states that democracy, development and respect for all human rights and fundamental freedoms are interdependent and mutually reinforcing’(74). To uphold human rights and ‘environmental rights’(75), and for ‘the maintenance of peace’, people require ‘media freedom’ in order to ‘seek, receive and impart information’(74), free of unaccountable censorship. STARDIT has been created in order to help anyone uphold these universal rights, by providing a way to share open access information in a structured way with a transparent process for quality checking.

Cultural neutrality

Values, assumptions, ways of thinking and knowing are not shared universally. The participatory process used for developing STARDIT required and will continue to require that it attempts to map cultural variations, in an attempt to avoid unconsciously reinforcing particular (often ‘dominant’)(76) values. Transparent acknowledgement of differing values and perspectives is critically important, in particular when mapping if different stakeholders’ values are complimentary or opposing. A participatory process requires mapping all of these perspectives and, where possible, involving people in labelling different perspectives and values. For example, STARDIT has already been used to map the varying perspectives of multiple stakeholders when planning a multi-generational cohort study(77).

Many problems facing humans are shared by non-human life forms and ecosystems, including rapid climate change, air pollution and sea-level rise. If initiatives are to operate in inclusive, culturally-neutral ways, reconsideration of the language used to describe relationships between humans, non-human life and the environment is essential.(78) Environmental and social sciences are challenging and redefining colonial-era concepts of what can be ‘owned’ as property or who ‘owns’ (78,79). As a result, ecosystems such as rivers and non-human animals, are being assigned ‘personhood’(80–82). For example, a public consultation by a ‘dominant’ group might ask, ‘who owns the rights to the water in a river system?’(76) This question imposes the dominant group’s values on people who may not share the same concept of ‘ownership’. In this way, Western European legal and economic traditions are frequently incompatible with those of some Indigenous peoples’.(78,83,84)

270 The participatory process used for developing STARDIT has attempted to be transparent about how
271 different stakeholders have been involved in shaping it in order to improve how the system can be used
272 to map values and provide more culturally neutral guidance for planning and evaluating involvement in
273 initiatives. However, it is acknowledged that it will be a challenging process to ‘de-colonialise’ and ‘de-
274 anthropocise’ language and action(85,86), as this may be perceived as a challenge to some people’s
275 cultural attitudes which may not align with the United Nation’s universally enshrined principles of
276 democracy, human rights and environmental rights. In addition, ongoing co-design will be required to
277 ensure STARDIT is as accessible and inclusive as possible.

278 Development phases and methods

279 Both the STARDIT Alpha version (0.1) and the Beta version (0.2) have already involved many people
280 from diverse disciplines and backgrounds in the development, as this is integral to its effectiveness
281 (Figure 1). It has been co-created using methodologies informed by PAR and other health research
282 reporting guidelines.(87) PAR describes related approaches which involve experts (such as researchers),
283 the public and other stakeholders “working together, sharing power and responsibility from the start to
284 the end of the project”.(88,89)

285 The Alpha version of STARDIT (version 0.1) followed the recommendations of a 2019 scoping review,
286 which mapped public involvement in global genomics research.(8) This was followed by an additional
287 review which mapped international guidance for planning, reporting and evaluating initiatives [insert
288 pre-print citation]. The work was also informed by a number of PAR projects, (37,40,41) and a report for
289 the Wikimedia Foundation by the charity Science for All.(90)

290 The charity Science for All has hosted the co-creation process since 2019. Science for All is a charity
291 based in Australia which support everyone to get involved in shaping the future of human knowledge,
292 with co-created values guiding their work(91). Development was informed by a number of literature
293 reviews and guidelines, with methods of involving people in the development of STARDIT guided by the
294 Enhancing the Quality and Transparency of Health Research (EQUATOR) network’s approach to
295 developing reporting guidelines.(87,92). Methods of involving people included public events, online
296 discussions and a consultation process.

297 The co-creation process is being supported pro-bono by Science for All, and has also received in-kind
298 support from the EPPI-Centre and individuals from multiple organisations worldwide. A modified Delphi
299 technique was used at some stages, with this method to be reviewed when co-creating future
300 versions.(93,94) Many people were invited to provide feedback on all aspects of STARDIT, including its
301 feasibility, design and implementation. They could comment anonymously using online forms and
302 shared documents, in online discussion forums, via email or during face-to-face or video meetings.

303 Science for All hosts an online working group which continues to guide the development of STARDIT
304 according to the terms of reference(95). Anyone is welcome to join the working group, contribute to
305 discussions and vote on decisions and ensure alignment with other initiatives. More detailed
306 information about the consultation process for the Alpha and Beta versions up to May 2021 can be
307 found in a 2020 and 2021 report (96,97). Further information about who was involved in the Beta
308 Version development and proposed future development phases can be found in the supplementary
309 information. STARDIT and all associated work and logos are currently licensed under Creative Commons
310 license (Attribution-NonCommercial-NoDerivs CC BY-NC-ND), with the quality of any future iterations
311 being the responsibility of not-for-profit host organisations and future licensing decisions to be made
312 transparent, with anyone invited to be involved. Figure 1: STARDIT development

313

314 Version One implementation

315 Once STARDIT Beta (version 0.2) has been submitted for publication, work will begin on the next
 316 version, (version 1.0). Those involved with STARDIT development will disseminate information, gather
 317 feedback and recruit more people and organisations to participate as project partners and potentially
 318 funders. This stage is estimated to take between 2 to 3 years, at which point a working group will
 319 formally invite other appropriate partner organisations (such as the UN and WHO) to adopt the STARDIT
 320 framework. A Steering Group will be established to oversee and continually improve the STARDIT
 321 system. STARDIT will require continued working with publishers, research funders and governments to
 322 encourage adoption of the reporting tool. More detail on the proposed next stages can be found in the
 323 [supplementary materials in the section 'Development phases'](#).

324 Scope and applications

325 STARDIT is the first and only data-sharing system that enables standardised sharing of data about how
 326 people are involved in any type of initiative, across any discipline, including involvement in the planning,
 327 evaluation and reporting of initiatives. In addition it allows comparison of both evaluation methods and
 328 any impacts or outcomes in relation to standardised terminology. Table 1 summarises the proposed
 329 scope and potential applications of the STARDIT.

330 Table 1: Example applications of STARDIT

Area	Sub-Area	Relevant data categories
Research	Health research	Reporting: Funding, conflicting or competing interests, co-design, experts involved, people affected involved, methods, process for deciding and measuring outcomes, protocols, who is accountable for ensuring protocol is followed, information about data storage, sharing, ownership and custodianship, information about data security practices and standards, information about consent and withdrawal processes evaluation of entire
	Social research	
	Genomics research	
	Environmental research	

Area	Sub-Area	Relevant data categories
		research process, ethical review, information about data analysis and data validation
Policy	Health and social policy	Reporting: Values of people involved, sources of data and evidence, data on past and current initiatives and spending(98), process for policy (or proposed policy) creation, process for deciding and measuring outcomes, experts involved, people affected involved, policy or manifesto writers, conflicting or competing interests of people involved, purpose of policy (what needs have been identified, how and by who), outcomes from policy (including outcomes measured by those affected by policy), policy evaluation (reporting if it achieved what was intended)
	Other government policy (transport, arts, education, environment etc)	
	Foreign policy	
	Proposed policy (including draft policy and manifestoes)	
	International development	
Education and learning	Educational initiatives	Reporting: Sources of data and evidence for intervention, purpose of intervention, process for educational intervention creation, funding, conflicting or competing interests, experts involved, people affected involved, conflicting or competing interests, process for deciding and measuring outcomes, outcomes from intervention, evaluation of intervention, ethical review
Arts	Community arts projects	Reporting: Purpose of project, process for project design and implementation, experts involved, people from communities intended to benefit involved, funding, conflicting or competing interests, process for evaluating project, project evaluation, project outcomes.
	Arts funding	Reporting: People involved in deciding funding process, purpose of funding, people allocating funding (funding sources), funding amount, conflicting or competing interests, process for deciding outcomes of funding, evaluating the funding allocation process
Information, media and cultural heritage	Health and medical information	Reporting: People involved in researching, writing (including medical writers), creating, reviewing (including peer reviewers), disseminating and funding, information about any potential risks (to human health or lifeforms, natural or cultural heritage), information about who assessed those risks and how (for example, medical information standards(99)), information about consent to appear in images and verified appearances of public figures, information about ownership of data or knowledge (including concepts of intellectual property, copyright and license information, relevant blockchains and non-fungible tokens), evaluating knowledge translation, reporting impacts and outcomes.(90)
	Disaster and emergency communication	
	Public interest, factual information commentary, documentaries and other informative media	

Area	Sub-Area	Relevant data categories
	Intangible cultural heritage (including folklore, traditions, language), traditional, local and Indigenous knowledge and wisdom	Reporting: who created any content containing the Indigenous or traditional knowledge, what tasks they had, how this knowledge was shared and any relevant concepts of 'owning' or 'property'; reporting who knows certain things (for example, people who are recognised as 'Preservers of Important Intangible Cultural Properties'(100)); reporting who is recognised as an Elder, community leader, Indigenous elders or leaders (and by who); reporting who does or does not have permission to verify, share, redact or edit content (including stories, beliefs, cultural practices and medicine)(101); information about data custodianship(56), information about any potential risks (to human health or lifeforms, natural or cultural heritage); information about who assessed those risks and how, information about informed consent process, information about any cultural sensitivities or restrictions (including relevant information about gender, clan, tribe or other culturally constructed groupings)(102–104), information about relevant laws and lore(56), ethics processes (including who was involved and how), reporting impacts and outcomes from dissemination.(90)
	Tangible cultural heritage (including cultural property(105))	Reporting: Who was involved in creating the property, any concepts of ownership or guardianship in relation to the property, data about ongoing management (including monitoring, exhibiting, restoring or moving), data about cultural significance and stakeholders involved in defining this
	Hardware designs (including hardware architecture, device designs or other abstract representations)	Reporting: Who was involved in creating the designs and how, who reviewed them and how (including relevant safety, regulation or standards information), what formats are the designs shared as and in what medium, information on license(s), outcomes and impact of the hardware
	Coding and algorithms	Reporting: who created code (including algorithms), who is involved in reviewing and scrutinising code (including who is involved in which ethical review processes), what code is part of which distinct projects or forks, what language the code is in, what medium (for example, machine or DNA), information about ownership of data or knowledge (including concepts of intellectual property and copyright), purpose of code, outcomes and impact of the code

Area	Sub-Area	Relevant data categories
Management and monitoring	Environmental and natural heritage, natural resource management	Reporting: data about who was involved in service design, monitoring and management processes, data about funding for monitoring or management (for example, funding for pollution monitoring), data about how information will be stored and shared (including what will be redacted and data security), data about who decides what data will be redacted and how this decision is made, information about how data will be analysed (including relevant code and algorithms) and how learning from data will be shared, information about relevant data privacy legislation and regulation
	Public and private essential services management (health, infrastructure, waste and recycling, water and sewage, electricity)	
	Data management and monitoring	
Evaluation	Process evaluation	Reporting: data about processes (industrial, public health, organisational)(5), people involved, outcomes
	Evaluation of participatory methods (co-design)	Reporting: data about participatory research methods and compare outcomes.
	Transparent rating	Reporting: Processes of transparency rating (or ‘scoring’) data quality about initiatives based on how much information about the initiatives is shared in a publicly accessible way (or reasons for redaction, including Indigenous knowledge).
Production, consumerism and business	Industry standards	Reporting: Internal processes and data sharing practices of self-regulating industry standards (for example, the Forest Stewardship Council, Marine Stewardship Council(50) and Certified B Corporations(51)), data sharing principles, process evaluation (including by those affected).
	‘Green’ industries and eco-tourism	Reporting: Transparent process for defining ‘green’ and ‘eco’, experts involved, people affected involved, process for deciding and measuring outcomes, outcome measures, evaluation of process.
	Infrastructure, construction and interiors	Reporting: Transparent reporting of sources of building and furniture materials, such as wood (including relevant DNA information to verify sources of timber), metals and other materials (including information verifying the supply chain is slavery free), data from building and structural assessments
	Finance and financial services	Reporting: who is involved in decision making (including investment and divestment), who scrutinises decision making, who is involved in holding individuals to account and who scrutinises this process, competing or conflicting interests of people involved in decision making, data about how concepts such as ‘ethical investments’ are defined, impacts or outcomes from investments or donations, data

Area	Sub-Area	Relevant data categories
		sharing practices and security practices, data about who scrutinises security practices.
	Donation and philanthropy	Reporting: Any stated purposes or caveats for donation, organisations or individuals donating, how money was spent, who was involved in deciding how it was spent, what was the method for deciding this, who is accountable for overseeing this, any outcomes or impacts.
	Other products (medical devices, electronics)	Reporting: Experts involved in production, other people involved in production process, resources involved in production process (including relevant DNA information to verify products from plants, animals and fungi), ingredients, funding for resources (for example demonstrating it is 'slavery free'), process reporting (including Good Manufacturing Practice), regulation and authorisation processes (for example medicines and medical devices), code and algorithm checking (for example, autonomous vehicles) process for designing impact assessment, impact assessment (including human and environmental), experts involved in dismantling process (including recycling), other people involved in dismantling process and disposal, evaluation of product according to transparently decided outcome measures
Products for human use or ingestion	Food	
	Medicines	
Products for non-human lifeforms	Food	
	Medicines	
	Other products	
Health Technology assessment	Assessment process for pharmaceuticals, devices, procedures and organisational systems used in health care	Reporting: Process for deciding health technology assessment (oversight and scrutiny), sources of data and evidence, process for deciding and measuring outcomes, experts involved, people affected involved, conflicting or competing interests, outcomes from assessment decisions (including outcomes measured by those affected by assessment decisions), collation of adverse event reports from Governments and reputable sources, assessment evaluation (did it achieve what was intended?), results of economic evaluations
Health and social care and services	Health care and services	Reporting: Process for assessing needs (including who was involved, the method and budget), process for prioritisation of services (including budgets and 'rationing' decisions), process for designing and implementing service or care (including who was involved, the method and the budget), process for evaluating service or care (including impacts), patterns for evaluating service improvement initiatives, process for reporting adverse events and malpractice (including the overview and scrutiny of this process), process for identifying patterns of sub-optimal service, process for responding to malpractice or other
	Social care and services	
Other services		

Area	Sub-Area	Relevant data categories
		identified issues, process for identifying impact indicators (including geolocation data)

Further examples of how STARDIT can be used are provided in the supplementary information, including; using STARDIT in genomic research for mapping phenotypes and reporting who was involved in helping define and describe them; providing data to critically appraise information sources (including public videos); report data about case studies consistently; creating ‘living systematic reviews’ and training machine learning from STARDIT data.

Using STARDIT

Across all disciplines, ‘plan’, ‘do’ and ‘evaluate’ are recognised as distinct stages of initiatives(106). While there are many ways to involve different people in these stages, standardised reporting and thus evidence-informed methods of doing so are lacking.(6,8,107) Figure 2 describes how STARDIT can be used to map how people might be involved in designing, doing, reporting and evaluating initiatives, starting with ‘idea sharing’.

Figure 2: Planning and evaluating initiatives using STARDIT

Reporting initiative design in STARDIT

Questions such as, ‘Who decides how people are involved?’ and, ‘Who is involving whom?’ and ‘what are people’s preferences for ways of working’ can be difficult to answer and is an active area of research(38,108). For example, planning a healthcare initiative requires input from experts as well as from the people the initiative is intended to help(107). Figure 3 summarises a way of using STARDIT to report the design process of initiatives, with Table 2 providing details about how involvement from different stakeholders can be reported at different stages. The section ‘Detailed reporting of design

352 using STARDIT' in the supplementary resource 'STARDIT Manual Beta Version' provides more
 353 comprehensive information.

354 Figure 3: Reporting initiative design in STARDIT

355
 356 Table 2: Summary of reporting initiative design in STARDIT

Initiative stage	Data reported
Stage 1: Idea identified: An idea for an intervention, project or research is identified and articulated	Report planned initiative
Stage 2: Idea refined The idea is refined with a small group of stakeholders(6,25,109–114)	
Stage 3: Stakeholder mapping: Existing stakeholders attempt to map who is included and who might currently be excluded from the process(25,115)	Preference Mapping
Stage 4: Co-create communication plan Develop a communication plan to invite people to co-create involvement(25,109,116)	
Stage 5: Share plan: Share the idea (according to the communication plan) and ask for feedback on it (including the involvement plan) (114,117,118)	Report updated plan
Stage 6: Analyse feedback: Collect and analyse feedback, share results. (116)	
Stage 7: Finalise idea and involvement plan: Co-create the plan (including the plan for involving people), seek relevant permissions and ethics (119,120)	Report final plan
Do initiative (see 'Planning and reporting initiatives using STARDIT')	
Stage 8: Evaluate involvement: Evaluate the process and the impact of both the initiative and involving people in the initiative	Report end of initiative

Mapping preferences for involvement

Involving multiple stakeholders in designing how people should be involved in initiatives is considered best practice, as it may facilitate power sharing and improve the process overall.(8,121) Current explanations of participatory research methods, and the language used to describe them, vary considerably. There is no agreed, consistent way to describe how people have been involved in a research initiative, or to report the impacts of their involvement.

The STARDIT Preference Mapping (STARDIT-PM) tool provides a standardised way to report the preference of multiple stakeholders. Anyone can be involved in creating a STARDIT report, which means that data on the impacts and outcomes of participation can be contributed by diverse stakeholders. Such reports will help researchers make informed decisions when planning participation in research.

For example, a recent study showed how a charity for people affected by a rare disease involved a small number of people affected by the rare disease in discussing preferences for how best to involve the wider community of people affected in future research prioritisation and planning(38). Those involved had a good understanding of any specific needs or preferences for involvement, and shared preferences for the tasks (such as overseeing data access), method (facilitated discussions) and mode of involvement (online text-based discussion). The STARDIT-PM data about this processes showed a preference for being involved using online discussions, and the STARDIT report stated that involving people influenced the way the charity planned to involve people prioritising research in the future.(40)

Examples of completed STARDIT-PM can be found in the additional files of a number of research projects(37,40,42). Table 3 summarises questions which can be asked to map stakeholder preferences with respect to involvement in initiatives.

The first stage of preference mapping requires individuals to self-identify as belonging to a specific grouping of people. People from that grouping then share views on how people from other groupings could be involved (or which groupings should not be involved). For example, labels for such groupings could include:

- only people with a professional role in the initiative
- everyone (any member of the public who is interested)
- anyone who might be indirectly affected by the initiative
- only people who are directly affected by the initiative
- only people who are participating in the initiative

- only people with a financial interest in the initiative.

As a consistent mapping tool for use across all initiatives, STARDIT would allow both comparison of diverse stakeholder views and exploration of similarities and variations in relation to preferences for involvement. Used alongside other planning tools, this information could help align initiatives with stakeholders' preferences. In this way, how stakeholders are involved throughout an initiative could be co-designed from the outset. Analysis of the data about preferences should involve stakeholders from multiple groupings to ensure that a diversity of perspectives are involved in assigning meaning to any data.

Table 3: Questions for mapping preferences for involvement

Question	Rationale for question
Which stakeholder group does this person align with?	To establish which grouping(s) the person identifies as being part of – for example 'researcher' or 'participant' (noting any groupings should be co-defined)
Describe any financial relationship or other interest this person has to this project	To provide a public record of any potential conflicting or competing financial interest
Views on the purpose and values of the research	To establish the purpose of the research, and the motivations and values of the initiative from multiple perspectives
Describe how you think the learning from this initiative could be used	To establish views about knowledge translation and application of learning
Views on who data from this project should be shared with and how	To establish that person's view about data sharing and ownership
Views on who should be involved (which 'groups' of people) – including who should not be involved – <i>following answers may be categorised depending on the stakeholder group</i>	To establish that person's views on which 'groups' of people they think should be 'involved' in research – that is, having a role in shaping the research design, direction and outcomes <i>Note: Answers may require sub-</i>

Question	Rationale for question
	<i>categories if there are multiple categories for who should be involved (see Figure 4)</i>
Views on specific tasks of this person or group	To establish that person's views on the tasks of the specific stakeholders who they think should be involved.
Preferred modes of communication	To establish that person's preferences on communication modes with stakeholder groups
Views on what methods should be used	To establish that person's views on which methods should be used to involve people – for example 'online survey'
Views on facilitators of involvement	To explore that person's perceptions of what might facilitate involving specified groups of people and help inform the design of involvement
Views on barriers of involvement	To explore that person's perceptions of what might be a barrier to involving specified groups of people and help inform the design of involvement
Views on what the outcome or output of the involvement could be	To ascertain the expectations of that person about what involving the specified groups of people might achieve
Views on which stage of the research this group should be involved?	To establish that person's views on which stage of the research the specified groups of people should be involved in

Beta Version interface

The data fields in the STARDIT system are summarised in Tables 4. Table 4 presents the full version of the data fields. The **'Minimum Contribution Reporting Form'** (MICRO) specifies the minimum information required to make a STARDIT report and these fields are indicated by an asterisk in the table (*).

Authorship

Acknowledging those involved in reporting ensures accountability for accuracy and increases trust in report content. STARDIT reports must be completed by named people who are accountable for the data being reported. Ideally, a public persistent digital identifier (for example, an ORCID number)(122) or an institutional email address will be linked to authors' names using Wikidata.

Reports cannot be completed anonymously, but STARDIT editors can redact author details from publicly accessible reports for ethical reasons (such as privacy or risks to safety).

Report authorship can be led by any stakeholder, including people associated with, or affected by, the initiative such as employees, researchers, participants, or members of the public. The affiliations of people formally associated with the initiative can be shared in a report.

Submission and Editorial process

Reports can currently be submitted to STARDIT via a simple online form or emailed as a document file. Editors review content for quality control (for example, checking that publicly accessible URLs align with the data in the report), but will not critically appraise the initiatives or methods. The Editorial process is currently parallel to the WikiJournal process, involving selected Editors from these journals. While Editors will not approve the ethics of the initiative, a transparent process for considering ethical issues will be considered before publishing a report. The Editors may consider questions such as, 'Does data need to be redacted in order to prevent harm and protect or preserve life?' or, 'Is personal information being shared without consent?' For more information about the Editorial process for reviewing data quality and ethical considerations, see the section 'Editorial and peer review of STARDIT reports' of the supplementary resource 'STARDIT Manual Beta Version'.

Once approved by the Editors, the STARDIT data will be entered into the database in a machine-readable format using structured data, based on the widely used Resource Description Framework (RDF) developed by the World Wide Web Consortium (W3C), which is used by Wikidata.(123) Each STARDIT report is assigned a unique Wikidata item number and all previous versions are navigable in a transparent history.

In future versions, it is proposed that stakeholders will be able to submit reports directly via an application programming interface (API) which will facilitate machine automation of STARDIT report creation). In addition, machine learning algorithms could be programmed to generate STARDIT reports from existing databases. As humans and machines submit reports, categories or meta-tags will be suggested (such as 'patient', 'member of the public'), with the option of adding, or co-defining, new categories using the Wikidata system for structured data.(124)

The database will generate a unique version number for the report with a Digital Object Identifier (DOI). To create an immutable version, the report will also be using the Internet Archive (a charity which allows archives of the World Wide Web to be created, searched and accessed for free)(125). Finally, the report will be assigned a status, with the data quality checking being described as:

- manually added, no human review (low quality checking – no DOI assigned)
- machine added, no human review (low quality checking – no DOI assigned)
- human review (medium quality checking – DOI assigned pending Editorial decision)
- peer or expert reviewed, with publicly accessible sources for indicators and references checked (higher quality checking – DOI assigned pending peer or expert review).

Processes for data checking and assigning report status need to be further developed and agreed by the STARDIT working group. For example, developing a transparent process if a report has been created about an initiative with no involvement from anyone associated with the project, or only one subset of stakeholders. In such cases, the Editorial team might give a short period of time for any other stakeholders to be involved in checking and editing any information.

Updating reports

STARDIT will enable reports to be updated as initiatives progress over time. Updates will be reviewed by the STARDIT Editors. Once an update is approved, the system generates a new version number, while also preserving the original report. Updates might include, for example, information about involvement in the initiative, or about dissemination, translation, co-creation of new metrics to assess impacts, or longer-term outcomes.(126)

Table 4: Summary of STARDIT Beta Version data fields

A minimum dataset is required for a STARDIT report. This is called the Minimum Contribution Report (MICRO). The 23 MICRO categories are indicated below with an asterisk (*). Relevant Wikidata items and qualifiers for these fields are provided in the supplementary materials in the section [‘Developing taxonomies and ontologies’](#) and on the Science for All STARDIT Beta webpage(39).

Section	Data category	Data field
Initiative context - This information locates the initiative within a clear context.	Identifying information	*Initiative name
		*Geographic location(s)
		Date range (start and end dates of initiative)
		Purpose of the initiative (aims, objectives, goals) *
		*Organisations or other initiatives involved (list all if multi-centre)
		*Funding information (link to publicly accessible URL if possible) - <i>this may include the project funder or, funding agreements, grants or donations</i>
		Clinical trial registration details (if applicable)
		*Ethics approval information (if applicable)
		Relevant publicly accessible URLs/URIs*
		Link: Description:
		Other relevant information (free text)
		RAiD (API) - identifier for research activities (if applicable)
		Keywords or metatags – including relevant search headings (e.g. Medical Subject Headings - MeSH)

Section	Data category	Data field
	Stage or state of initiative	<p>*At which stage of the initiative or research project has this report been written? Select from:</p> <ol style="list-style-type: none"> 1. Before the initiative– this report is prospective or describes planned activity 2. Ongoing – the initiative is still taking place 3. After the initiative has occurred
	Methods and paradigms	<p>*Methods of the initiative (what is planned to be done, or is being reported as done). Include information about any populations or eco-systems being studied, any ‘interventions’, comparators and outcome measures (qualitative or quantitative).</p> <p>If appropriate, include a link to a publicly accessible document (such as a research protocol or project plan).</p>
		Include any information about theoretical or conceptual models or relevant ‘values’ of people involved with this initiative, including any rationale for why certain methods were chosen
Report authorship – Information about who completed the report and how <i>Please note this section can be completed multiple times if there are multiple authors</i>	Identifying information for each author <i>(authors can be anonymised in the public report but at least one verified identity will need to be sent to WikiJournal Editors to attempt to prevent falsified reports)</i>	*Name
		*Publicly accessible profiles, institutional pages
		*Open Researcher and Contributor ID (orcid.org)
		Tasks in report completion
		Other information
	Accountability	*Key contact at initiative for confirming report content (include institutional email address)
	Date	Date of report submission <i>(automatically generated)</i>
Involvement in initiative Who is involved in this initiative and how?	Details about how each group or individual was involved in the initiative	<p>*Who was involved or how would you label those involved (select from group labels or submit new group label name in free-text) <i>You can name individuals or use ‘labels’ to describe groups of people such as ‘professional researchers’, ‘service users’ or ‘research participants’. Additional ‘labels’ or ‘meta-tags’ to describe people may be added if appropriate.</i></p>

Section	Data category	Data field
Editors assessing involvement may need to use the STARDIT 'Indicators of involvement' tool		How many people were in each grouping label?
		*Tasks of this person or group (list as many as possible) – <i>including any information about why certain people were included or excluded in certain tasks (such as data analysis)</i>
		Method of doing task? How did these people complete these tasks? (what methods were used) – <i>for example 'group discussion' or 'reviewing documents'</i>
		Communication modes? What modes of communication were used – <i>for example, 'group video calls', 'telephone interviews' or 'postal survey'</i>
		How were people recruited, contacted or informed about these tasks?
	Involvement appraisal	Methods of appraising and analysing involvement (assessing rigour, deciding outcome measures, data collection and analysis)
		Enablers of involvement (what do you expect will help these people get involved – or what helped them get involved)
		Barriers of involvement (what do you expect will inhibit these people from getting involved – or what inhibited them from getting involved). Are there any known equity issues which may contribute?
		How did the initiative change as a result of involving people (did the design or evaluation change?)
	Involvement outcomes, impacts, learning or outputs	*Were there any outcomes, impacts, learning or outputs from people being involved? <i>When describing these, attempt to label which groupings were affected and how. These can include impacts on people, organisations, processes or other kinds of impacts.</i>
	Stage	Which stage of the initiative were these people involved? (select from list of pre-defined stages or allow 'other')
	Cost and time	What was the estimated financial cost for involving people. How much time did it take. Were there any costs that cannot be measured financially?

Section	Data category	Data field
	Resources	Were there other resources needed aside from time and money (and if so what were they)?
	Learning points	What worked well, what could have been improved? Was anything learned from the process of involving these people?
Mapping financial or other 'interests'	Costs	What was the estimated financial cost for the initiative. How much time did it take. Were there any costs that cannot be measured financially (eg. volunteer time)?
	Financial or other interests (including personal or professional interests)	*Describe any financial relationship or other interests anyone involved with this project might have
		*Describe any conflicting or competing interests (including any relevant information about authors of this report), or any other 'interests', including personal interest or (for example, how you may be personally or professionally affected by the outcome of the initiative).
Data (including code, hardware designs or other relevant information)	Hosting and storage	*Who is the data from this initiative shared with?
		*How is it stored and hosted?
	Analysis	Who is involved in analysing the data? (align with terms used to describe who is involved)
		What methods will be used to analyse the data (including a link to any relevant code and information about validity)
	Dissemination	*How is information about this data disseminated?
	Ownership and control	Who 'owns' the data or claims any kind of 'intellectual property' or rights (include relevant licensing information)
		Who controls access to the data, how are decisions about data access made? Is data anonymised or de-identified? What methods are used for re-identification? What is the risk of unauthorised re-identification?
	Management and quality	Who manages (or 'curates') the data?
		Who is accountable for ensuring the quality and integrity of the data? (this may be an individual or organisation)
	FAIR criteria(127)	*How is/will the data be 'Findable, Accessible, Interoperable, Reusable' according to the FAIR criteria? (provide a link to a publicly accessible URL if appropriate)
	CARE principles(128)	If any data relates to Indigenous peoples, describe how data governance aligns with the CARE Principles for Indigenous Data Governance.
Impacts and outcomes	What was learned	*What new knowledge has been generated? (if appropriate, include effect size, relevant statistics and level of evidence)

Section	Data category	Data field
	Knowledge translation	Describe how the learning or knowledge generated from this initiative has or will be used
	Outcomes	*Has anything changed or happened as a result of this initiative that isn’t captured in previous answers?
	Measurement and evaluation	How has or how will this be measured or evaluated?
		Who is involved in measuring or evaluating this?
		Who was or is involved in deciding on the outcomes used to evaluate any impacts or outcomes? How were they involved?
Information completed by Editors		
STARDIT report version number (assigned)		Report number assigned to distinguish it from any future updated reports
Indicators completed by Editors and/or peer reviewers	Indicators of involvement	Use the STARDIT ‘Indicators of involvement’ tool
	Indicators of FAIR	Use the FAIR criteria(127)
	Indicators of translation and impact	
	Other indicators	
Editors and peer reviewers assessing the report will need to look for indicators in the following categories on publicly accessible URLs*		

Discussion and future versions

STARDIT is the first system that enables sharing of standardised data about initiatives across disciplines. By using Wikidata, STARDIT will make use of existing infrastructure capable of co-defining types of data in multiple languages(99,129,130). The co-design process (hosted by the charity Science for All) ensured people from multiple organisations and countries were involved in both creating and refining STARDIT, ensuring it is usable and relevant in multiple disciplines. Consultation with experts, and source materials from around the world, have informed the design of STARDIT. Co-authors come from disciplines including health research and services, environmental research and management, economics, publishing with over 20 different institutions represented. Future versions should be informed by a regular, systematic search, review and appraisal processes, using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) data set(131), used for reporting in systematic reviews and meta-analyses.

STARDIT enables reporting of who was involved, any impacts of stakeholders' involvement, and outcomes of initiatives over time. This functionality addresses a serious limitation of the current peer-reviewed publication process in which articles are not easily updated. However, there is no single process for making decisions that would improve and refine the processes, language and taxonomies associated with reporting initiatives, including who was involved in which tasks.(132) Similarly, based on feedback from Indigenous community leaders, patient representatives and others, it is essential to ensure access to learning and development opportunities is available to support people to both access and create STARDIT reports. The STARDIT project therefore needs to continually appraise the inclusiveness and effectiveness of its multidisciplinary, multilingual system, including accessibility of interfaces. To achieve this, the project will continue to work with its partner organisations, including the Wikimedia Foundation, a global leader in this field.

While there are multiple methods for mapping values,(133,134) there is currently no agreed, standardised way to map the values (beliefs and personal ethics) of those involved in initiatives and those creating reports in STARDIT. Further research is needed to facilitate mapping of values and detect whether certain perspectives are being consciously or unconsciously excluded.

STARDIT seeks to be an easy-to-use way for people from multiple disciplines to share data about initiatives. However, amassing sufficient reports to create a useful database is estimated to take at least 5 years, and will likely require machine learning. For example, adversarial machine learning may be used in parallel with humans (for verifying data) to generate STARDIT reports from existing publicly accessible data at a scale and speed otherwise impossible for humans alone to achieve(135). Similarly, the process of creating 'living systematic reviews' from STARDIT reports is currently theoretical and would require significant development and rigorous testing to realise.

It is important to note that access to Wikidata is actively blocked by governments or internet service providers in some countries. While such censorship limits people's ability to contribute or critically appraise data, STARDIT has been designed to be both interoperable with existing standards, and 'future proofed' to allow interoperability with existing and emerging data systems beyond Wikidata.

Science for All will continue to host the co-creation process and to monitor and evaluate the project. However, an open, transparent governance process that enables anyone to be involved in decision making and ongoing co-design of STARDIT will need to be established, and is proposed in the supplementary resources.

Ensuring that the STARDIT development process is inclusive and ethical, and that the database is quality assured, is paramount to ensuring that STARDIT is credible, useful and trustworthy. STARDIT currently relies on volunteers and pro-bono services from not-for-profit organisations. In the future, people should be paid for certain tasks, especially if the project is to avoid excluding the involvement of those from lower socio-economic backgrounds who may not be able to afford to volunteer their time. For the success and longevity of this project, a sustainable, transparently decided funding model needs to be established, which ensures both the independence of the data, the hosting process and the governance.

Conclusion

This article summarises work to date on developing **Standardised Data on Initiatives** (STARDIT), an open access web-based data-sharing system for standardising the way that information about initiatives is reported across diverse fields and disciplines. It outlines ways it has currently been used by different initiatives, and the next stages of development in detail. In accordance with the principles of transparent participatory action research, the authors invite the involvement of any interested persons in developing

515 and improving the next version of STARDIT, Version 1.0. Detailed and up-to-date information about
516 STARDIT is available on the Science for All website.(136)

517 **Declarations**

518 **Ethics approval and consent to participate**

519 Not applicable

520 **Consent for publication**

521 All authors, people named in acknowledgements and people identified in supplementary materials have
522 given consent for this to be published.

523 **Availability of data and materials**

524 Supplementary data can be found in the supplementary files, with further data available in the associated
525 STARDIT report for this article: [insert link].

526 **Competing interests**

527 No authors have declared any competing or conflicting interests

528 **Funding**

529 No funding has been received for this project directly. Many people have volunteered their time and
530 expertise. Organisations which have provided in-kind support include the charity Science for All (hosting
531 and facilitating the co-design process) and the EPPI-Centre, who hosted an in-person meeting in 2019.

532 **Authors' contributions**

533 Jack Nunn conceived of STARDIT, conceived of and led the co-design process, facilitated face to face
534 events, facilitated online discussions and decision making processes, analysed data, designed and carried
535 out the evaluation of the process and the reporting (including STARDIT and GRIPP2 reports), wrote the
536 manuscript and collated and integrated feedback from public consultations.

537 Thomas Shafee provided critical input and feedback on early versions of STARDIT, built the working
538 STARDIT Beta version in WikiData and provided feedback on multiple versions of STARDIT.

539 Steven Chang provided insight into early versions of STARDIT and provided feedback on multiple versions
540 of STARDIT.

541 Richard Stephens, Jim Elliot, Sandy Oliver, Carolyn Thompson and James Ansell provided input at the first
542 STARDIT event and provided feedback on multiple versions of STARDIT.

543 All other authors provided detailed feedback on the STARDIT manuscript.

544 **Authors' information**

Affiliation numbering	First name	Middle initial	Last names	Affiliation
-----------------------	------------	----------------	------------	-------------

1	Jack	S.	Nunn	Director of Science for All (Education Charity registered in Australia), Melbourne, Australia
2	Jack	S.	Nunn	School of Public Health, La Trobe University, Victoria, Australia
3	Thomas		Shafee	School of Life Sciences, La Trobe University, Victoria, Australia
4	Steven		Chang	La Trobe University, Victoria, Australia
5	Richard		Stephens	Patient Advocate, Co-Editor-in-Chief, 'Research Involvement and Engagement'
6	Jim		Elliot	Public Involvement Lead at Health Research Authority (England)
7	Sandy		Oliver	Professor of Public Policy at UCL Institute of Education
8	Denny		John	Evidence Synthesis Specialist, Campbell South Asia, New Delhi, India
9	Denny		John	Adjunct Assistant Professor, Amrita Institute of Medical Sciences & Research Centre, Kochi, Kerala, India
10	Maureen		Smith	Cochrane Consumer Executive Co-chair
11	Neil		Orr	Department of Linguistics, Faculty of Medicine, Health and Human Sciences, Macquarie University
12	Neil		Orr	Poche Centre Indigenous Health, The University of Sydney
13	Jennifer		Preston	University of Liverpool
14	Josephine		Borthwick	University of Melbourne
15	Thijs		van Vlijmen	Taylor and Francis
16	James		Ansell	Consumers Health Forum of Australia
17	Francois		Houyez	European Organisation for Rare Diseases
18	Maria		Sharmila Alina de Sousa	Independent research and development consultant
19	Roan	D.	Plotz	Applied Ecology and Environmental Change Research Group, Institute for Sustainable Industries and Liveable Cities, Victoria University, Melbourne, Australia.
20	Jessica	L	Oliver	Australian Citizen Science Association
21	Yaela		Golumbic	University of Sydney
22	Rona		Macniven	The Poche Centre for Indigenous Health, Faculty of Medicine and Health, The University of Sydney, NSW 2006, Australia
23	Rona		Macniven	School of Population Health, Faculty of Medicine and Health, University of New South Wales, Sydney 2052, Australia;
24	Rona		Macniven	Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney 2109, Australia
25	Samuel		Wines	Co-Labs Melbourne
26	Ann		Borda	The University of Melbourne

27	Ann		Borda	University College London
28	Håkon		da Silva Hyldmo	Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services
29	Pen-Yuan		Hsing	University of Bath, United Kingdom
30	Pen-Yuan		Hsing	MammalWeb project
31	Lena		Denis	Johns Hopkins University
32	Carolyn		Thompson	Institute of Zoology, Zoological Society of London
33	Carolyn		Thompson	University College London

545

546 Acknowledgements

547 The authors wish to acknowledge the support the following people have given to the STARDIT project so
548 far. The following people have agreed to be named as project supporters (in order of project support):

- 549 1. Sir Iain Chalmers, Cochrane (co-founder)
- 550 2. Tom Calma, University of Canberra (Chancellor)
- 551 3. Simon Denegri, The Academy of Medical Sciences (Executive Director)
- 552 4. Mick Mullane National Institute of Health Research, UK
- 553 5. Chloe Mayeur, Sciensano
- 554 6. Wannes Van Hoof, Sciensano
- 555 7. Nicholas Gruen, King's College London, (visiting Professor)
- 556 8. Magdalena Wailzer (Open Innovation in Science Center, Ludwig Boltzmann Gesellschaft)
- 557 9. Marc Tischkowitz, University of Cambridge (Professor of Medical Genetics)
- 558 10. Sally Crowe, Crowe Associates (Director)
- 559 11. Anubhav Nigam, Lake Zurich High School (Student)
- 560 12. Jennifer Morris
- 561 13. Monica Westin, Google (Google Scholar partnerships lead)

562 The authors would also like to thank:

- 563 ● Pauline Sanders and Pauline Stobbs for their valuable assistance in editing versions of the
564 manuscript
- 565 ● Saloni Swaminathan for her valuable assistance in supporting the associated scoping review and
566 collating data
- 567 ● Paul Lacaze for his valuable input throughout the STARDIT project so far
- 568 ● All the Science for All volunteers who have supported this project

569

Supplementary materials

Change Log from Alpha version

A number of aspects of STARDIT have been altered from the Alpha version as a result of the co-design process. Below is a summary.

- Plain English summary and introduction rewritten in order to provide a clearer introduction
- Added categories to STARDIT reporting framework about data sharing and purpose of research in preference mapping to capture more nuanced views about preferences in power sharing
- Added categories to the STARDIT report in order to capture data about the purpose of research
- Built a working version of STARDIT reports and form for submitting them
- Multiple other changes, summarised in the public consultation report (97)

Development phases

Alpha version development

The Alpha version was co-created with a small team of experts from a number of different disciplines, informed by their work with diverse communities around the world(137). The initial Alpha version was informed by a number of frameworks and models (see supplementary materials 'Models which inform the standardised reporting framework'). A modified Delphi technique was used for some stages of the development, with this method to be reviewed to future versions(93). Draft versions were shared with co-authors and final decisions were made using an online decision making system, hosted pro-bono by the not-for-profit organisation Science for All, working in partnership with the Wikimedia Journals. The team co-created a method to invite feedback and improvement from as many people as possible in the development of the beta version. The Alpha version was published as a pre-print, allowing anyone in the world to view it.

Beta version development

Once the Alpha version was published, people could provide feedback anonymously using online forms, in online discussion forums and at face to face and online discussions. A face to face event was held in London with participants from other countries joining online, including Australia and Belgium. The co-creation process and public consultation is described in more detail in the 'STARDIT Public Consultation Report – September To December 2019'(96).

The Alpha version author team invited public feedback on the pre-print. A link to the paper and a feedback form was shared on a publicly accessible URL, on the Science for All website and via the authors' social media and email networks.

Decisions about the reporting framework were made using voting process on an online decision making system, hosted pro-bono by the not-for-profit organisation Science for All,(138) working in partnership with the Wikimedia Journals.

A pre-print version of the Beta **[this current version]** was shared online and the public were again invited to give feedback through an online form, shared document, online discussion forum or via email. People who gave feedback were invited to be a co-author, contributor or named in the acknowledgements, in accordance with the guidelines of the Committee on Publication Ethics (COPE)(139), with transparent reporting of who did which tasks and the author order determined by the order in which people joined the

610 STARDIT project. Once feedback has been collated, an updated version of the 'STARDIT Public Consultation
611 Report' will be created and cited in the version of the STARDIT Beta version submitted for peer-review.

612 **Version 1.0 development**

613 Once STARDIT Beta (version 0.2) has been submitted for publication, work will begin on the next version,
614 (version 1.0). Those involved with STARDIT development will disseminate information, gather feedback and
615 recruit more people and organisations to participate as project partners and potentially funders. This stage
616 is estimated to take between 2 to 3 years, at which point a working group will formally invite other
617 appropriate partner organisations (such as the UN and WHO) to adopt the STARDIT framework. A Steering
618 Group will be established to oversee and continually improve the STARDIT system. The working group and
619 Steering Group will continue to be hosted by Science for All, although the Steering Group will be able to
620 vote on a decision to change or involve other host organisations. STARDIT will require continued working
621 with publishers, research funders and governments to encourage adoption of the reporting tool. Future co-
622 creation processes should be decided collaboratively, informed by international best-practices(140).

Using Standardised Data on Initiatives (STARDIT): Beta Version Manual

About this document

The purpose of this manual is to provide all the information required to understand and use Standardised Data on Initiatives (STARDIT). As STARDIT evolves and develops, so will this manual. This is the first version of this manual, which has been written as a supplementary resource for the STARDIT Beta version.

This manual was written by Jack Nunn (January 2021) with the assistance of Thomas Shafee and in-kind support from the charity Science for All.

What is the purpose of STARDIT?

Standardised Data on Initiatives was created to help everyone in the world find and understand information about collective human actions, which are referred to as 'initiatives'.

What is STARDIT?

STARDIT is an initiative that anyone in the world can get involved in, an idea owned and controlled by no one person, government or other kind of organisation. STARDIT is an idea about how data could be shared about initiatives, and an aspiration to make as much data as possible readable and understandable by both humans and machines.

The Alpha and Beta versions of STARDIT are suggestions for what kind of data could initially be standardised, how this data can be checked for quality, how this data can be shared and other suggestions about how the initiative should be governed transparently. The Beta version is a starting point, answering the questions 'why', 'what if' and 'how?' to the question 'how can humanity understand what it is doing?'.

Who is involved in STARDIT?

Anyone in the world can get involved in the STARDIT initiative. STARDIT is designed and run using a 'participatory action research' paradigm, which aims to involve all stakeholders (the public, experts and others with a 'stake' in the work) in every aspect of the initiative. In plain English, anyone can get involved and have a say in how it should be designed and run, with all decisions made transparently and stored in a publicly accessible way.

The participatory action research process is currently being hosted pro-bono by the charity Science for All. This means that Science for All hosts and supports the process for designing STARDIT, making collective decisions, and reporting this process. It is proposed the development of STARDIT will continue to be hosted by the not-for-profit organisation 'Science for All', although co-designing a tender process may be necessary for future versions as the workload inevitably increases.

The STARDIT initiative is currently using the Wikimedia Foundation's Wikidata project to host STARDIT data and reports, using structured, machine readable data.

STARDIT is also working with people from multiple partner organisations to help align the initiative with the ways of working of other organisations to make it as useful as possible. Other partners include experts from La Trobe University, Campbell South Asia, Health Research Authority (England), members of the Cochrane Advocacy Advisory Group, the Evidence for Policy and Practice

Information and Co-ordinating Centre (EPPI-Centre), the Poche Centre for Indigenous Health (Sydney University), the UCL Centre for Co-production in Health Research and John Hopkins University.

The names of the authors and project supporters as of August 2021 can be found in the STARDIT Beta version.

Every person involved in STARDIT (and therefore any organisations they may represent) must agree to uphold the defined values and act within the code of conduct defined in this document.

How is STARDIT being developed?

STARDIT will continue to be transparent in how it is governed and how decisions are made, with the entire process open for anyone to be involved. Open online discussion forums and public events will inform decision making and future co-design processes. The data-sharing system will be designed to be both interoperable with existing standards, and future proofed to allow continuous improvement and data inter-operability.

What are the values of STARDIT?

As STARDIT is a new initiative, we have adopted the values of Science for All, the organisation which is hosting the participatory action research process.

Summary of values

1. We are not-for-profit – our motivation is not profit but working for all life on earth
2. We value the freedom to ask any question, using the scientific method wherever possible
3. We support the principles of democracy, the ‘rule of law’ and evidence-informed policy wherever we can
4. We are transparent and accountable
5. We include as many people as we can, as best we can in every aspect of our work
6. We know that science means knowledge, and knowledge takes many forms

STARDIT values

- 1. We are not-for-profit – working for all life on earth**
 - We value outcomes that everyone is involved in creating – including ones which could be measured in biodiversity, happiness indexes and often – are currently immeasurable.
 - We recognise the need to be inclusive, and therefore, to pay people for their time, skills and expertise. When we work in economic structures, we do so only to support our values, not to make profit at the expense of others.
 - We do not seek to impose our values (or other values such as economic outcome measures) on any life on earth.
 - We value human rights, but also note that ‘rights’ don’t start and end with humans – we seek to explore what ‘working for all life on earth’ means in any way possible.
- 2. We value the freedom to ask any question, using the scientific method wherever possible**
 - Asking a question can be the most simple, most profound or the most complex thing we can do as a species. Questions like ‘why?’ and ‘why not?’ are powerful.
 - The freedom to ask the questions is essential, and we hope to support people everywhere to ask any question they feel is important.
 - Some questions can be answered using the ‘scientific method’ – which essentially seeks to build our knowledge by asking questions, making observations about the available reality and using this to make predictions. If the predictions can be tested – or are

repeatable – others can verify results. We value this method of asking questions, ‘peer review’, sharing open data and results – new knowledge, for free, for everyone.

- We recognise the limits of the scientific method and that some things can never be ‘known’ or ‘peer reviewed’.

3. We support the principles of democracy, the ‘rule of law’ and evidence-informed policy wherever we can

- We support the United Nation’s statement on democracy, including that ‘democracy is a universal value’ and that the principles of ‘democracy, development and respect for all human rights and fundamental freedoms are interdependent and mutually reinforcing’¹.
- We also accept that there is no single model of democracy and that democracy does not belong to any country or region. To uphold human rights and for ‘the maintenance of peace’, we agree that people require ‘media freedom’ in order to ‘seek, receive and impart information’(73)
- We support decisions and policies which are informed by evidence, preferably created from open data, shared freely and peer-reviewed by those who are collectively defined as experts. We do not support decisions or policy which appears to be informed by real or perceived conflicting or competing interests. We do not align with any political ‘parties’ or ideologies, and will only work with elected representatives to help uphold the values articulated in this document.
- We recognise ‘law’ and ‘lore’ as forms of knowledge which must evolve and interact with reality and language. We support universal access to this kind of knowledge. We believe the purpose and enforcement of these laws must be collectively decided in the interests of all life on earth. We support the principle of the rule of law, which implies that every person is subject to the law, including people who are lawmakers, law enforcement officials, elected representatives and judges. However, we recognise that that are often multiple, sometimes competing or conflicting systems of ‘law’ and ‘lore’, and concepts of ‘property’. We will always be guided transparently and collectively when navigating any conflicts or competing interests.

4. We are transparent and accountable

- We support transparent decision making, reporting and evaluation.
- We aspire to be as transparent as possible. We will always publicly disclose any funding or ‘in kind’ donations. Partnership with organisations will always align with these values.
- We recognise that real or perceived conflicting or competing interests can damage trust, and we will do everything we can to avoid any doubt in regards to the motives of our actions being anything other than aligned with our values.
- We accept that some things may have to be confidential (for example, storing confidential personal information to align with privacy laws) and we will always work transparently, inviting everyone to be involved in helping us get the balance right between privacy and transparency as the world evolves with new technologies.
- We expect and encourage others to hold us to account, to make sure we do what we say we do, and act as we say we do. Transparency is the best tool to enable this.
- We will always try to understand the effect or impact of our actions – and work openly with anyone who can help us improve how we are measuring this. This will help ensure we are doing things the best way we can.

5. We include everyone we can as best we can in every aspect of our work

¹ http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/64/155

- ‘Organisations’ are people working together towards a shared goal or purpose – and everyone is welcome to get involved.
 - We will be transparent about who is involved, how we are supporting people to stay involved, how we are working to involve new people and will always welcome ideas about how we can improve this.
 - Ensuring we are inclusive and do not knowingly ‘exclude’ anyone is central to our way of working
- 6. We know that science means knowledge, and knowledge takes many forms**
- We recognise that knowledge takes many forms – this includes people who are subject area experts, people with personal experience, people with traditional, indigenous or local knowledge, artists – and those with big dreams and big ideas
 - Linguistic labels like ‘knowledge’, ‘skills’, ‘expert’, ‘artist’, ‘patient’ and ‘citizen’ can be both helpful and unhelpful. Wherever possible we will include people in helping us define what we mean when we use these words.
 - Some things are knowable, some things are not – we work to explore the limits of what knowledge means – with everyone, for all life on earth.

Additional values and paradigms

In addition to Science for All’s values, the following values are specific to the STARDIT initiative:

- STARDIT is **system and language agnostic**, it should always be designed to work across and with as many systems as possible, in as many countries and languages as possible
- STARDIT **designs and code should always be open access** and relevant licenses should always be those which allow others to build on and improve the project, while maintain central control over quality (such as the Creative Commons Attribution-NonCommercial-NoDerivs CC BY-NC-ND license and the GNU General Public License (GPL) 3.0 for code)
- STARDIT **development will be guided by the participatory action research (PAR) paradigm**(70). PAR is an umbrella term which describes a number of related approaches, including (89), community-based participatory research, participatory action research (including critical participatory action research), participatory health research, community-partnered participatory research, cooperative inquiry. It may also include other forms of action research embracing a participatory philosophy which may include ‘co-design’ of research and other kinds of research which might include forms of ‘public involvement’ (or sometimes ‘engagement’).
- STARDIT will be guided by the **United Nations rights-based paradigm**, including human rights, environmental rights and other emerging rights

Immutable values

While these values will evolve, we will keep an immutable record of our values. They will always be shared via a publicly accessible URL and [regularly archived](#) on the ‘Internet Archive’ for future reference(125).

Our values will be reviewed annually – with a process for involving the public, with final approval going to a vote in the Steering Committee. This review process may change over time but will always require and invite specialist, expert and public scrutiny, according to the transparent governance principles described in the manual.

STARDIT must be implemented in a way which encourages those involved to acknowledge cultural values and assumptions in a transparent way. For example, some people can be labelled as having human-centred (anthropocentric) values, which values natural resources in relation to benefits they can provide for humans. In contrast, some people who think the value of nature should be measured using non-human outcomes can be labelled ecocentric(141). A participatory process requires mapping all of these perspectives and, where possible, labelling them.

What is Standardised Data?

People and organisations share data in different ways around the world, in multiple languages. While ways of standardising data have been around for millennia, many ways are still specific to certain areas of knowledge or geographical regions and are often not inter-operable, or at best, hard to access or interpret.

For humanity to survive, and to live in balance within the eco-systems which sustain all life on earth, we need to understand what has already happened, what humanity is currently doing, who is doing it, why, and what the effects are. Answering these questions is very complex, and sometimes impossible.

By standardising ways of sharing data about human action, we can allow both humans and machines to start linking data, start asking new kinds of questions, and empower anyone in the world to be able to answer them. Machine readable data will allow data to be interpreted in new ways.

What is an ‘initiative’

We use the word ‘initiative’ to describe any intervention, research or planned project. Examples include:

- **Research project** – any organised activity undertaken to answer a question. This includes data collection and analysis to help answer future questions which may arise. Projects may be nested within one another – the report context should clarify this.
- **Project or initiative** - any organised activity with planned outputs or outcomes.
- **Educational intervention** – any organised activity designed to improve people’s knowledge, understanding or skills(60,61)
- **Evaluation** – an attempt to evaluate an action or phenomena, including related impacts and outcomes. This includes program or policy evaluation

What is a STARDIT report?

A STARDIT report contains standardised data, collected into a ‘report’ which contains a minimum set of data required to describe a collective human action (an ‘initiative’) for a STARDIT report at a certain point in time. The minimum amount of data required for a STARDIT report is called a ‘**Minimum Contribution Report**’ (STARDIT MICRO), with the ability to add additional information to this minimum dataset.

STARDIT reports can be created at any point of an initiative, including before, during and after. While they must describe an initiative at a fixed point in time, the reports can be updated to created updated versions of the same report, by updating or adding data.

Making more open, machine readable, interoperable, and multilingual

Developing taxonomies and ontologies

Developing taxonomies and ontologies will be an ongoing process facilitated by the current Wikidata infrastructure, and may require creating additional tools to create more inclusive ways of involving people in developing taxonomies.(142) By using the Wikidata initiative, those involved can work to group concepts and code them, aligned with existing taxonomies.(99) Examples of existing taxonomies include the National Library of Medicine’s Medical Subject Headings(143). Terms with clear and easily defined descriptions will be assigned a code. This infrastructure may also aid machine learning, analysis by neural networks and other forms of artificial intelligence (AI), similar to the ‘Cochrane Crowd’ project(144).

The current STARDIT data fields are mapped below to existing Wikidata items, with a link to the most up to date version found here: https://wikispore.wmflabs.org/wiki/STARDIT/form_mapping

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
Core: Initiative context	Identifying information	Initiative name	Len	Compulsory
		Geographic location or scope	P937	Compulsory

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
		Purpose of the initiative 'stated as' free text	P3712 P3712 Q P6001	Compulsory
		Start date of initiative	P580	Compulsory
		End date of initiative	P582	
		Organisations or other initiatives involved	P664	Compulsory
		Ethics approval (org)	P793 Q98550700 P1027	
		Ethics approval (date)	P793 Q98550700 P585	
		Ethics approval (ID)	P793 Q98550700 P1932	
		Funding sources (org)	P8324	Compulsory
		Funding sources (dept or scheme or grant ID)	P793 Q P1932	
		Relevant URLs	P856	
		keywords, metatags, mesh terms, raid terms	P921	
	Stage or state of initiative	Date of report	P793 Q37260 P518 Q10870555 P793 Q37260 P585 or P793 Q37260 P580 and P793 Q37260 P582	Compulsory

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
		Methods of the initiative (what is planned to be done, or is being reported as done)	P4510	Compulsory
		Link to a publicly accessible methodology document	P4510 Q P973	
		theoretical or conceptual models or relevant 'values' of people	P4510	
Input: Report authorship & status	How was this report generated?	Name of report author (person or algorithm)	P50	Compulsory
		ORCID	author item P496	
		Publicly accessible profile / institutional page	author item P856	
	Accountability	Key contact email at initiative for confirming report content	P793 Q37260 P968	Compulsory
	Report data review status	Who has checked the quality of the data in this report?	P4032	

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
Input: Involvement in initiative	Involvement details for each contributor	Who was involved (named individual, organisation)	P767	Compulsory
		Who was involved (group of anonymous individuals acting in role)	P767 Q P1114	
		Specific tasks of this person or group	P767 Q P2868	Compulsory
		Methods of involvement of participants	P767 Q P2283	
	Outcomes and outputs	What was the outcome or output of the involvement?	P1542	Compulsory
		Were any publication produced as part of this?	P921	Compulsory
	Involvement appraisal	Methods of appraising and analysing involvement (assessing rigour, deciding outcome measures, data collection and analysis)		
		Facilitators of involvement (what helps the contributors in achieving the	P1552 Q101097118 P5102 P1552 Q101097118 P6001	

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
		project's outcomes?) 'stated as' free text		
		Barriers of involvement (what inhibits the contributors from achieving the project's outcomes?) 'stated as' free text	P1552 Q16515105 P5102 P1552 Q16515105 P6001	
		What was the outcome or output of the involvement of these people? What changed as a result of involving people? Were there any impacts?	P767 Q P1542	
	Stage	Which stage of the initiative were these people involved?	P767 Q P585 or P767 Q P580 and P767 Q P582	
	Cost and time	What was the estimated financial cost for involving each person or group	P767 Q P2130	
		How much time did it take to involve each person or group Were there any other non-financial costs	P767 Q P2047 P767 Q P1542	

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
		in involving each person or group		
Input: Financial or other interests	Financial or other interests	Financial relationship or other interest this person has to this project	P767 Q P1932 P1542 Q99429881 P6001	Compulsory
		Conflicting or competing interests 'stated as' free text	P1552 Q99429881 P1932 P1552 Q99429881 P6001	Compulsory
		What was the estimated financial cost for the overall initiative. How much time did it take.	P2130 P2047	
Output: Research data	FAIR data produced	Findable: How is information about this data disseminated	P1056 Q42848 P1552 Q100451967 P1056 Q42848 P7228	Compulsory
		Accessible: How is it stored and hosted	P1056 Q42848 P4945	Compulsory
		Interoperable: What analyses were	P4510	
		Interoperable: What format is it in	P1056 Q42848 P2701	
		Reusable: Access restriction status	P1056 Q42848 P7228 Q66739888	Compulsory

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
	Sensitive data produced	Reusable: License	P1056 Q42848 P275	
		Who owns it	P1056 Q42848 P1552 Q2587068 P1056 Q42848 P127	Compulsory
		Where is it stored	P1056 Q42848 P276	Compulsory
		Access restriction status	P1056 Q42848 P7228	Compulsory
		How to access (email)	P1056 Q42848 P968	
		How to access (url)	P1056 Q42848 P2699	
		Data steward/curator	P1056 Q42848 P1640	
Output: Impacts and outcomes	Outcomes	Has anything changed or happened as a result of this initiative that isn't captured in previous answers?	P1542	Compulsory
	What was learned	What new knowledge has been generated? (if appropriate, include effect size, relevant statistics and level or evidence)	P1542 Q133500	Compulsory
		What part of the initiative was the learning about	P1542 Q133500 P518 P1542 Q133500 P921	

Section	Data category	STARDIT field	Wikidata encoding	MICRO Compulsory
		What topic was learned		
	Knowledge translation	Describe how the learning or knowledge generated from this initiative has or will be used	P1542 Q133500 P1542	
	Measurement	How has or how will this be measured?	P1542 Q P459	
		Who is involved in measuring this?	P1542 Q P767	

Visual language and logo development

A culturally neutral logo was required for STARDIT in order for it to be recognised, including one which does not contain Latin alphabet letters so it could work across other scripts. Working with a professional graphic designer, the logos were co-designed, with anyone invited to give feedback and rank their favourite options. Inspiration for the logo was drawn from multiple traditions, with both tally sticks and DNA codons being integrated into the design of the logo, both systems of knowledge transfer which require a complementary half, representing the checking or tallying of the STARDIT data.

Future versions of the logo could contain Quick Response (QR) codes around the logo which link to report DOIs, to allow people to scan them easily on portable internet connected devices with cameras. Figure 4 is a mock up of such a QR code, linking to the first ever STARDIT report. Additional information about the data quality of each report could also be embedded in the logo by with colours which can be discriminated by those who have a decreased ability to see colour or differences in colour.

For legal reasons, and to prevent uncontrolled use of the STARDIT logos and artworks, the 'STARDIT' name and other associated 'intellectual property', all of the aforementioned is owned by the charity Science for All. Discussions about ownership, and any transfer of such ownership to another organisation or persons will be made transparently, according the governance processes outlined in this document. The project welcomes advice and feedback on this.

Figure 2: Full logo with Latin Alphabet name

Figure 3: Icons

Figure 4: Icon with Quick Response codes

Using STARDIT

Creating a report – Beta version

A working version of the reporting framework can be used at this address:

<https://wikispore.wmflabs.org/wiki/STARDIT>

This page also includes examples of human- and machine-readable filled in forms, and a link to the data mapping used to convert between these.

A stable link can be found at: <https://scienceforall.world/stardit/beta/>

Detailed example applications

Example 1: Mapping phenotypes

STARDIT has an additional potential application in reporting who was involved in defining phenotypes, which is relevant to genomics, other ‘omics’ and other areas of research including mental health(8,145). Transparent reporting of who was involved and how in defining and describing ‘qualia’ (subjective lived-experience) will be crucial in ensuring that phenotype data is high-quality. For example, while there may be Wikidata codes for different parts of the spectrum, colour deficiency in an example of subjective lived-experience based on genetic variation that can affect many aspects of life. While this is a relatively easy to understand example, there are countless variations that mean we all will experience the world differently, including variations which may affect mental health. STARDIT can describe who was involved in describing lived experiences of

phenotypes and any specific variations they may have. If such data is standardised across human languages and cultures (as much as is possible), this will facilitate such research, including machine learning.

Example 2: Providing data to critically appraise information

Organisations like Wikipedia provide an invaluable, impartial and free service for sharing information and works in partnership with multiple organisations including Google, Cochrane and many others. Trust in information underpins human civilisation. Ensuring that people can easily verify both who has created content, how, who funded it and who has reported information about this will allow both manual and automated checking of information sources. Google already uses Wikipedia to provide information about the authorship of YouTube videos and other information(146), and STARDIT could provide a much more detailed dimension to such reporting, which can be both viewed or edited by anyone.

Example 3: Reporting case studies

The STARDIT data-sharing system has been designed to align with case study methodology. It allows for multiple authors with different ways of analysing and interpreting data.(147,148) Multiple perspectives may aid understanding of any causal relationships by comparing (triangulating) data from different people, enhancing the reliability of the analysis²⁶. STARDIT provides a way of consistently sharing and comparing data while using the case study method, and aligns with existing case study reporting tools.(149)

Example 4: Living systematic reviews

To improve evidence-informed ways of involving people in research, and to understand what works, for whom, why, and in what circumstances, several reviews have called for standardised ways of reporting involvement over extended periods of time.(6–8) ‘Living systematic reviews’,(150) which can be continually updated, could potentially be generated from STARDIT reports, and would contribute to an evidence base informing best practice and future policy. Future versions of STARDIT could:

1. form a team to scope the feasibility of creating a ‘living systematic review’ based on data from STARDIT reports
2. work in partnership with relevant stakeholders to ensure the process for creating living systematic reviews is transparent and conforms to best-practice agreeing on data for inclusion.
3. aid machine learning, analysis by neural networks and other forms of artificial intelligence (AI), similar to the ‘Cochrane Crowd’ project(144).

Many other applications have been proposed, including aligning STARDIT with the Global Biodiversity Information Facility (GBIF). More detail on STARDIT + GBIF is summarised on the Science for All website(151).

Editorial and peer review of STARDIT reports

Presently, the process for publishing reports relies on the Editorial team at the WikiJournals. In the future, the process will be designed to include an open public and peer-review process where appropriate (noting that public review does not involve being reviewed by experts or peers, but may involve checking the quality of data sources and critically appraising data). The process described in this section will be constantly reviewed and transparently decided. Experts from multiple relevant disciplines including ethics, law and data security will be involved, with decision making processes hosted at publicly accessible URLs.

Validity and quality assurance of data

Processes for data quality assessment and assigning report status need to be further developed and agreed by the STARDIT working group, in order to decide when reports will be sent to humans for approval (authors or Editorial team), when it is necessary to confirm comprehension of an ethics statement, and what the public access will be to unchecked data. Existing systems have already implemented similar systems to quality assure 'research grade' data, and a high-quality process for deciding this will be central to the success of STARDIT Version 1.0.(152)

In future versions it will be necessary to further develop a transparent process if a report has been created about an initiative with no involvement from anyone associated with the project, or only one subset of stakeholders. In such cases, the Editorial team might give a standard period of time for any other stakeholders to be involved in checking and editing any information (similar to the concept of 'right of reply') before the report is published, or given the status 'human reviewed'. However, the process for deciding which stakeholders to contact and how to ensure equity (alongside capacity considerations of the Editorial team) is an area for active discussion and development in future versions. For example, ensuring Indigenous peoples who are stakeholders in a mining initiative have been involved in checking a STARDIT report about a mining initiative created by a company with a declared financial interest in the mining initiative might present challenges that it is not possible for the Editorial team to overcome. Such challenges could be labelled and incorporated as future data categories in the STARDIT reports, for example labels such as 'report not checked by all stakeholders' could be updated if more stakeholders have subsequently been involved in checking any report.

Data ownership and hosting

To reduce data sharing barriers and encourage reuse, a STARDIT report cannot currently contain any proprietary information that is not open access or publicly accessible, except for information volunteered by the report authors (such as institutional email addresses), much like a 'corresponding author' on a peer reviewed paper. The report is therefore citing information already hosted in a publicly accessible way. STARDIT allows authors to structure publicly accessible data in a standard format, and the STARDIT data system will allow this to be read in a machine-readable format. The role of Editors (and in later versions of STARDIT, public and expert or peer-reviewers) is to ensure that the publicly accessible data sources cited in the report align with the report content. Where possible, content of URLs will be automatically archived using independent not-for-profit archiving services such as the Internet Archive(125) in order to prevent links expiring and to preserve the URL data at the time it was reviewed by the editors.

‘Indicators of involvement’ report review tool

For editors or peer-reviewers reviewing the STARDIT report, it may be necessary to look for objective publicly accessible indicators, in order to verify reports in categories such as involvement and research data. This section provides a proposed method to transparently review and label involvement.

Background to involvement indicators

Concepts such as ‘involvement’, ‘ethics’ and ‘democracy’ cannot always be expressed fully in linguistic constructs, as they carry resonances of concepts such as equality, justice and human rights (153). A number of systematic and scoping reviews have attempted to map such concepts(8,154–156).

These indicators are an attempt to reduce subjectivity in describing ‘involvement’ by articulating in a standardised way what objective measures might exist which would suggest that ‘involvement’ (power sharing) is occurring, and for what purpose(88,157). The indicators can be grouped and categorised in the table below and yet all of them rely on a foundational assumption or axiom – which is that those affected by interventions or research are the people most appropriate to design and deliver it – recognising all skills and knowledge have equal value (88). The ‘UK Standards for Public Involvement in Research’ define indicators of involvement as ‘a statement of good practice that describes what is needed to demonstrate meeting the standard’(115). STARDIT aligns with this terminology, extending ‘indicators’ beyond public statements in order to incorporate other indicators, for example, governance documents or reported actions. Indicators may be either qualitative or quantitative data(158).

Defining the purpose of involvement

There may be intrinsic or extrinsic reasons for involving people (159). For example, the purpose or ‘driver’ of involving people might be to include personal experiences in order to improve the research (160), to abide by regulation or law, or to do it because there is evidence which indicates involving people will improve the research (161). A narrative review identified three broad value systems associated with involving people (133), which included values based on:

- ethical, human rights, equality, openness and accountability
- evidence based, objective assessments of effectiveness and consequences of involvement

For the purposes of this reporting framework, these have been categorised below as four broad ‘purposes’ of involvement.

Diagram of the purposes of involvement and measurable indicators

Purpose of involvement	Measurable indicators
Obliged: There are legal or other codified power constructs in place which oblige involvement in initiatives and research	<ul style="list-style-type: none">• Public statements about methods or paradigms of involvement• Public policy• Support for people to get involved• Reported actions

Post-positivist: lived (subjective) experience and knowledge is valued equally alongside other kinds of knowledge and data

Evidence-informed: There is evidence which suggests that involving people improves the quality and direction of initiatives and research

Self-evident: The concepts of ethics, human rights and democracy demand involvement

- Evidence of funding for involvement

Data sources can include: Peer-reviewed papers, governance documents, legal or government documents, legislation or policy documents, publicly accessible websites

Foundational principle

Those affected by initiatives are the people most appropriate to help design, deliver and evaluate it

Ethical review

In exceptional cases, the report may cite publicly accessible information that could cause harm to life (such as a report on poaching, corruption or other illegal activities) which may threaten the safety of the report authors if the information shared is undesirable to those in positions of power, or to those who may represent a real threat to the personal safety of authors or other lifeforms implicated in or impacted by a report. Authors are asked to self-assess their personal safety and that of others if disclosing personal information and are given the option of requesting to redact any identifying information from the report if they prefer. This request will be flagged on the report to indicate identity has been verified. The editorial team is not responsible for assessing this themselves (as all information is already publicly accessible), however they are required to flag with the report authors if they feel any personal or identifying information is being shared without consent.

Questions which editors should consider when reviewing a report include:

- Has data been sufficiently redacted in order to prevent harm and protect or preserve life?
- Is personal information being shared without consent?

It is not the responsibility of editors to ensure that publicly accessible content aligns with the values of other organisations and governments, as a central purpose of STARDIT is to create quality assured, peer-reviewed data immune from censorship (which is distinct from ethical redaction) and immune from future editing.

While STARDIT reports are immutable, if it is subsequently discovered that some information should be redacted for ethical reasons which were not apparent at the time of the report being published, this can be done so with an updated report, which will reflect which data field was redacted, by which author and for what reason. In extreme cases reports can be deleted, if approved by the Editorial team using a transparent decision-making process. Technical details on how this will be achieved will need to be constantly reviewed to balance ethical data hosting with database quality. If

STARDIT reports have been archived on other databases (such as archiving sites) it is the responsibility of respective data-hosts to comply with any requests for redaction or removal.

How does STARDIT work within ‘law’ and ‘lore’?

As stated by our values, “we recognise ‘law’ and ‘lore’ as forms of knowledge which must evolve and interact with reality and language”. In addition, “we recognise that there are often multiple, sometimes competing or conflicting systems of ‘law’ and ‘lore’, and concepts of ‘property’. We will always be guided transparently and collectively when navigating any conflicts or competing interests”.

At present, there is no universally accepted authority to enforce ‘international law’ upon sovereign states or individuals. Accordingly, STARDIT conduct will be guided by the United Nations on all matters of law, not any one sovereign state. This has special relevance for Indigenous peoples globally who may not either be represented by or recognise the sovereignty of some nation states(76).

Relevant statements from the United Nations which underpin STARDIT include Article 19 of the Universal Declaration of Human Rights, which states(73):

‘Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers’

In 2020, the United Nations Secretary-General stated ‘*purposes that involve data and analytics permeate virtually all aspects of our work in development, peace and security, humanitarian, and human rights*’, encouraging ‘*everyone, everywhere*’ to ‘*nurture data as a strategic asset for insight, impact and integrity – to better deliver on our mandates for people and planet*’(10).

For the purposes of concepts of intellectual property (including trademarks), and to protect STARDIT from being used by people in ways which are outside of the values defined in this document, any intellectual property (including logos or code associated with STARDIT) are currently owned by the charity Science for All, which is currently hosting the participatory action research process to create and manage STARDIT. Any decisions relating to the above (including transfer of ownership of any intellectual property) are to be made by the STARDIT Steering Committee, which hosted by Science for All, but independent of Science for All. In the future ownership may be transferred to an appropriate organisation established specifically for the purpose of owning such intellectual property, for example, establishing a charity called ‘Standardised Data International – STARDIT).

STARDIT will always defer to United Nations declarations in favour of any sovereign laws, and does not recognise itself as a legal entity which is acting in any one sovereign state. Citizens of non-UN-recognised states will be recognised as individual legal persons and included equally alongside any other person, regardless of status (including citizens, residents, asylum seekers and refugees).

STARDIT is an initiative to support individuals to self-organise ways of sharing information, and it is the responsibility of each individual (including individuals working on behalf of organisations) to act both within the values of STARDIT, and any laws to which they may be subject.

142 Recognising the limits of language and measures

143 STARDIT is not intended to be a way of explaining or expressing every aspect of reality or subjective
144 existence in words and data, but a way of collectively mapping and then standardising language and
145 data we are currently using as a species.

146 “I realized that the difference that I saw between things was the same thing as their unity,
147 because differences (borders, lines, surfaces, boundaries) don't really divide things from
148 each other at all, they join them together, because all boundaries are held in common”(162)

149 Alan Watts

150 The principle behind Goodhart’s Law is important in the future development of STARDIT to ensure
151 that the data collected, and how it is collectively structured does not have unintended consequences
152 (163). Goodhart’s Law can be summarised as “when a measure becomes a target, it ceases to be a
153 good measure”.(164)

154 While STARDIT may provide the basis for reporting data and facilitating future machine learning, the
155 data itself should be organised and structured collectively and transparently. Where possible is
156 should facilitate critical appraisal, rather than the data collection itself become a target or measure.
157 STARDIT should however encourage data reporting to improve the accessibility of data which can
158 inform such critical appraisal. Any ‘scoring’ or ‘rating’ of data beyond the quality of available data
159 would be in addition to anything already described and would need careful consideration and co-
160 design.

Models and papers which inform the standardised reporting framework

From here onwards will be updated once additional review is completed.

STARDIT has been informed by multiple models and reporting frameworks across many disciplines, and will be compatible with many of them and future-proofed to allow further development in the articulation of reporting.

Table 5 summarises the frameworks and models which informed this work and how.

The search strategy is summarised in the figure 'STARDIT models and framework search strategy'.

In order to inform future iterations, the authors suggest that future versions of STARDIT are informed by regular systematic search, review and appraisal, with the protocol published in PRISMA.

Figure 5: STARDIT models and framework search strategy

175 **Table 5: Resources which informed the standardised reporting framework**

176 This table contains a summary of sources which have informed STARDIT. Each source has a reference with more information provided in the references.

177 Peer reviewed sources are named after the first author, non peer-reviewed sources give the title, then the name of the publishing organisation. The table is

178 organised alphabetically by field and then by author.

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Shortell(165)	Peer-reviewed	Paywall access	2015	Accountable care organisations		Informed terminology to describe involving people in assessing priorities and outcomes of care, including in accountable care organisations
Aircraft Accident and Incident Investigation , International Civil Aviation Organization(166)	Not peer-reviewed	Paywall	2021	Aircraft incident investigation	International Standards and Recommended Practices for aircraft accident and incident Investigation	
Victorian Agency for Health Information(167)	Not-peer reviewed	Publicly accessible website	2020	Analysis and sharing of data (quality and safety of healthcare)		Informed ways of visualising data about the quality and safety of health systems
Dillon(168)	Peer-reviewed	Open access	2017	Assessing patient involvement in health research		Informed general terminology, including outcome measures for involvement

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Maccarthy(169)	Peer-reviewed	Open access	2019	Basic and preclinical health research	PPI Ready: Researcher Planning Canvas	Informed general terminology, including impact and values
Global Biodiversity Information Facility (GBIF)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (data sharing)		Informed terminology to describe international data sharing methodologies
Access to Biological Collection Data (ABCD), Taxonomic Databases Working group (TDWG)(170)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (Data standardisation)	Access to Biological Collection Data (Taxonomic Databases Working group)	Informed terminology to describe methods of standardised reporting of biodiversity
Biodiversity Information Standards, Taxonomic Databases Working group (TDWG)(171)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (Data standardisation)	Biodiversity Information Standards, Taxonomic Databases Working group (TDWG)	Informed terminology to describe methods of standardised reporting of biodiversity
Darwin Core, Darwin Core Task Group, Taxonomic Databases Working group (TDWG)(172)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (Data standardisation)	Darwin Core, Darwin Core Task Group, Taxonomic Databases Working group (TDWG)	Informed terminology to describe methods of standardised reporting of biodiversity
Ecological Metadata Language, National Center for Ecological Analysis and Synthesis(173)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (Data standardisation)	Ecological Metadata Language (National Center for Ecological	Informed terminology to describe methods of standardised reporting of

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					Analysis and Synthesis)	biodiversity, including metadata languages
World Geographical Scheme for Recording Plant Distributions, Taxonomic Databases Working group (TDWG)(174)	Not-peer reviewed	Publicly accessible website	2020	Biodiversity (Data standardisation)	World Geographical Scheme for Recording Plant Distributions, (Taxonomic Databases Working group)	Informed terminology to describe methods of standardised reporting of biodiversity in plants
Selinske(175)	Peer-reviewed	Paywall access	2019	Biological Conservation		Informed terminology to describe the social dimensions and outcomes of land management, including describing how people can have different 'functions' in their environment
Whitburn(176)	Peer-reviewed	Open access	2019	Biological Conservation		Informed terminology for describing and comparing behaviours as an outcome measure (for example 'pro-environmental behaviour') and synthesising data. Informed terminology for self-reports and 'construct validity'

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
CRedit taxonomy(177)	Not peer-reviewed	Publicly accessible website	2017	Biology	Contributor Roles (CRedit) taxonomy	Informed taxonomy to define author contributions to primary research papers
Medical Subject Headings (MeSH), United States National Library of Medicine(178)	Controlled and hierarchically-organized vocabulary	Open Access	2020	Biomedical and health information	Medical Subject Headings (MeSH)	Informed ways of structuring vocabulary and other terminology (including qualifiers) in a hierarchy, in a standardised way (including interoperability and API usage).
Shippee(179)	Peer-reviewed	Open Access	2015	Biomedical and health research		Informed general terminology, in particular terminology to articulate the stages of research
Shippee (179)	Peer-reviewed	Open access	2013	Biomedical and health services research		General terminology, description of research stages, informed search strategies
Mark2Cure(180)	Not-peer reviewed	Publicly accessible website	2020	Biomedical research		Informed terminology to describe a method of mapping key terms and concepts to identify connections

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Virtual Communities for Impact(181)	Not peer-reviewed	Publicly accessible website	2020	Building virtual communities		Informed terminology for co-creating communities, informed terminology and methodology for evaluating impact
B Impact Assessment(182)	Not peer-reviewed	Publicly accessible website	2020	Business		Informed ways of reporting impact for organisations and initiatives
Deverka(183)	Peer-reviewed	Paywall access	2012	Cancer Genomics	Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement	Informed general terminology and terminology specific to genomics research, as well as methods of assessing impact of involving stakeholders.
Embodied Carbon in Construction Calculator (EC3) tool	Not peer reviewed	Public domain	2019	Carbon emissions in manufacturing	Embodied Carbon in Construction Calculator (EC3) tool	Informed terminology to describe reporting of carbon usage
Climate Active, Australian Government(184)	Not peer reviewed	Public disclosure summary	2019	Carbon Neutral certification	Climate Active Standard Carbon Neutral Program	Informed terminology to describe standardised reporting of carbon usage
Charity Evaluation Working Group(185)	Not-peer reviewed	Publicly accessible website	2020	Charity evaluation (multidisciplinary)		Informed terminology for describing evaluating the work of charities and using

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						evidence informed decision making
Support Guidelines (Evaluation Support Scotland)(186)	Not-peer reviewed	Publicly accessible website	2020	Charity evaluation (multidisciplinary)	Support Guidelines (Evaluation Support Scotland)	Informed terminology to describe reporting initiatives, outcomes and other areas of initiatives.
Code of Fundraising Practice, Fundraising Regulator (UK)(187)	Public Domain	Open Access	2021	Charity financial reporting		Informed terminology to describe fundraising methodology
Australian Charities and Non-for-profit Commission, Australian Government(188)	Not peer-reviewed	Public domain	2021	Charity reporting		
Charity Navigator Methodology (189)	Not peer-reviewed	Publicly accessible website	2001	Charity research		Informed terminology for recording and comparing data about charities in a consistent way, in particular methods for rating accountability and transparency
10 Principles of Citizen Science, Australian Citizen Science Association(190)	Not peer-reviewed	Public domain	2018	Citizen Science		
Australian Citizen Science Project Finder, Australian Citizen Science Association(191)	Not peer-reviewed	Public Domain	2021	Citizen Science		Informed terminology to describe database of citizen science projects

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Citizen Science COST Action(192)	Not peer-reviewed	Publicly accessible website	2019	Citizen science	Citizen-Science Ontology, Standards and Data	Informed terminology to describe metadata-concepts, vocabulary and an ontology to support data sharing about initiatives. Also informed terminology to describe data ownership.
EU-Citizen.Science(193)	Not peer-reviewed	Publicly accessible website	2020	Citizen science		Informed terminology to describe citizen science
Göbel(194)	Not peer-reviewed (pre-print)	Open access	2019	Citizen science		Informed terminology to describe citizen science and open science
Göbel(195)	Peer-reviewed	Open access	2019	Citizen science		Informed terminology of governance and purpose of citizen science
SciStarter(196)	Not-peer reviewed	Publicly accessible website	2020	Citizen Science		Informed categorisation of citizen science projects
Soleri(197)	Peer-reviewed	Open access	2016	Citizen science		Informed terminology to describe citizen science and 'power' dynamics
Strasser(198)	Peer-reviewed	Open access	2019	Citizen science		Informed terminology, typology and political considerations of 'citizen

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						science' and participatory research
Ten Principles of Citizen Science, European Citizen Science Association (ECSA)(199)	Not-peer reviewed	Publicly accessible website	2015	Citizen Science	Ten Principles of Citizen Science (European Citizen Science Association)	Informed terminology to describe citizen science
Citscibio(200)	Not-peer reviewed	Publicly accessible website	2020	Citizen science (biomedical)		Informed terminology to describe citizen science in biomedical research
Borda(201)	Peer reviewed	Open Access	2019	Citizen science (health and biomedical)		Informed terminology to describe citizen science in biomedical and health research
QuestaGame Core Values(202)	Public Domain	Open Access	2020	Citizen Science (values)		Informed terminology to describe concepts such as 'values' and the 'purpose' of data collection
Sacristán(203)	Peer-reviewed	Open access	2016	Clinical research		Informed general terminology
Bloom(204)	Peer-reviewed	Open access	2018	Clinical Trials		Informed language to describe partnerships between different stakeholder groups (industry, academia, patients and public)

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Loudon(205)	Peer-reviewed	Open Access	2015	Clinical trials	PRECIS-2 tool	Informed terminology to describe clinical trials
Toolkit for Researchers and Research Organisations, Australian Clinical Trials Alliance(206)	Not peer-reviewed	Publicly accessible website	2019	Clinical trials		Informed terminology for evaluating and reporting involvement
Searchable FCC ID Database, Federal Communications Commission(207)	Not peer-reviewed	Public domain	2020	Communications standards		
McIllduff(208)	Peer-reviewed	Open Access	2019	Community Based Participatory Research	Model of Engaging Communities Collaboratively	Informed language to describe reporting of community based participatory research methods, including concepts such as 'community engagement' and 'implementation' (specifically in reference to Indigenous populations)
Jane Goodall Institute Australia	Not peer reviewed	Public domain	2018	Conservation		Informed terminology to describe reporting of conservation projects

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Impact Evaluation - Case Study: Bwindi Impenetrable National Park and Mgahinga Gorilla National Park Conservation Project, Global Environment Facility(209)	Not-peer reviewed	Publicly accessible website	2007	Conservation biology, eco-tourism		Informed terminology for reporting theories of change and other outcomes and impacts
Resource Description Framework (RDF), World Wide Web Consortium (WC3)(123)	not peer-reviewed	public domain	2014	Data	<u>World Wide Web Consortium (WC3) standards</u>	Informed structured data usage
Initiative for Open Citations(210)	Not peer-reviewed	Publicly accessible website	2020	Data interoperability (citations)		Informed terminology to describe citations data sharing
International Organization for Standardization (ISO)(211)	Not-peer reviewed	Publicly accessible website	2020	Data standardisation	International Organization for Standardization (multiple standards)	Informed terminology to describe management of international standards (including creation process for standards), including informing the design of STARDIT to align with ISO standards
Schema.org(212)	Not-peer reviewed	Publicly accessible website	2021	Data standardisation and structuring		Informed terminology for data structuring and to describe methods of collaboratively managing data standards

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Husereau(213)	Peer-reviewed	Open access	2013	Economic evaluations of health interventions	Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement	Informing terminology for economic outcome measures
Schagner(214)	Peer-reviewed	Paywall access	2013	Ecosystem mapping and management		Informed terminology for describing methods of mapping people's 'values' in the context of 'ecosystem services', including concepts such as 'site-specific policy'
Education Endowment Foundation(215)	Not-peer reviewed	Publicly accessible website	2020	Education		Informed terminology for standardised reporting of educational outcomes and evaluating educational interventions, including measuring concepts such as 'essential skills' and 'non-academic' outcomes, and using randomised controlled trials in an education context
SPECTRUM Database, Education Endowment Foundation(216)	Not-peer reviewed	Publicly accessible website	2020	Education		Informed terminology for standardised comparisons and review of 'non-academic' and 'essential skills' in relation to outcomes

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Star Portal, Australian Government, Office of The Chief Scientist(217)	Not peer-reviewed	Public Domain	2020	Education		
The International Database of Education Systematic Reviews (IDESR)(218)	Not peer-reviewed	Public domain	2021	Education		
Tikly(219)	Peer-reviewed	Paywall access	2015	Education (evaluation)		Informed terminology to describe ways of consistently defining concepts such as 'learning', including facilitators and barriers or learning.
Atlas of Life(220)	Not peer-reviewed	Public domain	2020	Environment		
GlobalFungi Database, GlobalFungi	Not peer-reviewed	Public domain	2020	Environment (fungi)		
Impact report 2019, International Tree Foundation(221)	Public Domain	Open Access	2019	Environmental		Informed data categories for reporting impact from tree planting
Mackay(222)	Peer-reviewed	Paywall access	2019	Environmental Psychology		Informed terminology for describing and comparing behaviours as an outcome measure (for example 'pro-environmental behaviour')

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
DataONE(223)	Not-peer reviewed	Publicly accessible website	2020	Environmental science		Informed terminology to describe data standardisation
Citizen Science Evaluation Rubric, Port Phillip EcoCentre(224)	Not peer-reviewed	Publicly accessible website	2019	Evaluating citizen science	Citizen Science Evaluation Rubric	Informed terminology and methods of evaluating citizen science
Reed(225)	Peer-reviewed	Open access	2018	Evaluating involvement and engagement in interdisciplinary research	A common standard for the evaluation of public engagement with research	Informed general terminology, informed ways of evaluating involvement in research and other data collection
Maccarthy(226)	Peer-reviewed	Open access	2019	Evaluating involvement in basic and preclinical health research		Informed terminology and evaluation, including involvement assessment survey
Barber(227)	Peer-reviewed	Open access	2012	Evaluating involvement in health and social research		Informed terminology to describe involvement in research, including evaluation and impact assessment
Crocker(21)	Peer-reviewed	Open access	2018	Evaluating involvement in health research		Informed general terminology, including assessing impact of

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						involvement in clinical trials and evidence synthesis
Edelman(228)	Peer-reviewed	Open access	2016	Evaluating involvement in health research		Informed general terminology, including evaluating involvement as part of research or initiative (not a distinct intervention)
Staley (18)	Peer-reviewed	Open access	2019	Evaluating involvement in health research		Informed general terminology, informed ways of describing learning as an outcome of involvement in research. Informed reporting methodology including language to describe reporting short, medium and longer term outcomes from involvement. Informed terminology to describe impacts from involvement.
United Nations Evaluation Group (UNEG)(229)	Not peer-reviewed	Publicly accessible website	2013	Evaluation of functions and products of UN entities	United Nations Evaluation Group (UNEG)	Impact evaluation informed by 'Impact Evaluation Guidance Document'
Guidelines and Standards for Evidence Synthesis in Environmental Management,	Not-peer reviewed	Publicly accessible website	2018	Evidence Synthesis (Environmental Management)	Guidelines and Standards for Evidence Synthesis	Informed terminology to describe evidence syntheses of data about environmental

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
The Collaboration for Environmental Evidence(230)					in Environmental Management VERSION 5.0	policy and practice as a public service
Guideline for Rapid Evidence Assessments in Management and Organizations, Center for Evidence-Based Management (231)	Not-peer reviewed	Publicly accessible website	2017	Evidence synthesis (organisational management)	Guideline for Rapid Evidence Assessments in Management and Organizations (Center for Evidence-Based Management)	Informed terminology for describing evidence assessment and synthesis
Supporting the Use of Research Evidence (SURE)(111)	Not peer-reviewed	Publicly accessible website	2011	Evidence-informed policy		Informed terminology to describe evidence-informed policy, informed terminology to describe stakeholders
External quality assessment Specification, Her Majesty's Treasury (UK)(232)	Public Domain	Open Access	2019	External quality assessment (Government services)		Informed terminology to describe external quality assessment for internal Government auditing
Royal College of Pathologists of Australasia Quality Assurance Programs, Royal College of Pathologists of Australasia(233)	Public Domain	Open Access	2020	External quality assessment (pathology testing)		Informed terminology to describe external quality assessment for pathology assessment

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
IRIS+ (234)	Not peer-reviewed	Publicly accessible website	2020	Finance	IRIS+ Standards	Informed terminology and metrics for reporting impact for organisations and initiatives
Standardized Forest Stewardship Council Forestry Management audit reporting, Forest Stewardship Council(235)	Not-peer reviewed	Publicly accessible website	2020	Forest management (reporting and auditing)	Standardized Forest Stewardship Council Forestry Management audit reporting	Informed terminology to describe forest standardised reports of data from audits and management
Open Geospatial Consortium Standards (OGC)(236)	Not-peer reviewed	Publicly accessible website	2020	Geospatial mapping	Open Geospatial Consortium Standards (OGC)	Informed terminology to describe standards in geospatial data
Standards and Interoperability Registry, Global Earth Observation System of Systems (GEOSS)(237)	Not-peer reviewed	Publicly accessible website	2020	Geospatial mapping	Standards and Interoperability Registry (Global Earth Observation System of Systems)	
The Online System for Central Accounting and Reporting (OSCAR), Her Majesty's Treasury (UK)(238)	Public Domain	Open Access	2020	Government financial reporting (UK)		Informed terminology to describe inter-departmental Government financial data
Digital Service Standard, Digital Transformation Office (DTO) Australian Government(239)	Not-peer reviewed	Publicly accessible website	2016	Government services (online)	Digital Service Standard	Informed standardised ways to describe online services which are 'simpler, clearer and faster for all users'

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
John F. Kurtzke(240)	Peer-reviewed	Open access	1983	Health	Rating neurologic impairment in multiple sclerosis: An expanded disability status scale (EDSS)	
Rosen(241)	Peer-reviewed	Paywall access	1997	Health	The international index of erectile function (IIEF): a multidimensional scale for assessment of erectile dysfunction	
Draper(158)	Peer-reviewed	Paywall access	2010	Health (community Participation)	Evaluation framework for the analysis of the process of community participation in health initiatives	Informed language to describe indicators for the assessment of community participation in health initiatives
South(242)	Peer-reviewed	Open access	2016	Health (patient and public involvement in clinical trials)		Informed terminology to describe involving people in clinical trials

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Chaplin(243)	Peer-reviewed	Open access	2020	Health (Pharmacogenetics)	STROPS guideline (STrengthening the Reporting Of Pharmacogenetic Studies)	
Wang(93)	Peer-reviewed	Open Access	2015	Health (reporting guideline development)		Informed terminology to describe guideline development, informed methodology of STARDIT development
Methodological Expectations of Cochrane Intervention Reviews (MECIR), Cochrane Methods(244)	Not peer-reviewed	Public domain	2020	Health (review standard)	Methodological Expectations of Cochrane Intervention Reviews (MECIR)	
Cochrane Handbook for Systematic Reviews of Interventions, Cochrane(245)	Public Domain	Open Access	2020	Health (Systematic reviews)	Cochrane Handbook for Systematic Reviews of Interventions	Informed terminology to describe methodology for conducting systematic reviews, including critical appraisal
Assessing the quality of information to support people in making decisions about their health and healthcare, The Picker Institute(246)	Not-peer reviewed	Publicly accessible website	2006	Health and healthcare information		Informed ways of describing standardised ways of assessing readability and usability of information.

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Health Literacy Universal Precautions Toolkit, Agency for Healthcare Research and Quality(247)	Not-peer reviewed	Publicly accessible website	2015	Health and healthcare information	Agency for Healthcare Research and Quality Health Literacy Universal Precautions Toolkit (Second Edition)	Informed terminology to describe assessing whether health information is easy to read and understand
Preparing written information for consumers that is clear, understandable and easy to Use, Australian Commission on Safety and Quality in Health Care(248)	Not-peer reviewed	Publicly accessible website	2019	Health and healthcare information	National Safety and Quality Health Service Standards (Australia), Standard 2: Partnering with Consumers	Informed terminology to describe clear health information
Toolkit for Making Written Material Clear and Effective, U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (249)	Not-peer reviewed	Publicly accessible website	2020	Health and healthcare information	Toolkit for Making Written Material Clear and Effective	Informed categories for describing clear communication
Clear Communication Index, Centers for Disease Control and Prevention Office of the Associate Director for Communication(250)	Not-peer reviewed	Publicly accessible website	2016	Health and healthcare information and communication		Informed terminology to describe methods to assess public communication materials, including 'scoring' of certain criteria of sources

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Statement on consumer and community involvement in health and medical research, National Health and Medical Research Council (Australia)(251)	Not peer-reviewed	Publicly accessible website	2016	Health and medical research		Influenced terminology for involving people in health and medical research
Patient and public involvement in health and social care research: A handbook for researchers, National Institute for Health Research(252)	Not peer-reviewed	Open access	2014	Health and social care		Informed terminology to describe people involved in research and evaluation of involvement
Brett(6,7)	Peer-reviewed	Open access	2014	Health and social care research		Informed general terminology, methods of assessing impact and informed search strategy
Smits(253)	Peer-reviewed	Open Access	2020	Health and social care research (planning involvement)	The “Involvement Matrix”	Informed write-up of co-design process to create a planning tool to support patient and public involvement in research.
Guidance on co-producing a research project (INVOLVE) (254)	Not peer-reviewed	Publicly accessible website	2018	Health and social research	Guidance on co-producing a research project (INVOLVE)	Informed general terminology, how people can be involved in stages of research

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Public involvement in research: values and principles framework, INVOLVE(134)	Not-peer reviewed	Publicly accessible website	2015	Health and social Research		
Pandya-Wood(255)	Peer-reviewed	Open access	2017	Health and social research (ethical public involvement)		Informed terminology to describe the stages of ethical public involvement in research before and during ethics approval processes
International Classification of Functioning, Disability and Health, World Health Organisation(256)	Not-peer reviewed	Public domain	2001	Health and wellbeing	International Classification of Functioning, Disability and Health (ICF)	
Wada(257)	Peer reviewed	Open Access	2020	Health and wellbeing		Informed terminology for involving people in explaining and disseminating research
Dissemination and Implementation Toolkit (PCORI) (258)	Not peer-reviewed	Publicly accessible website	2017	Health care		Informed terminology and assessment of involvement at the stages of dissemination and implementation
Dukhani(20)	Peer-reviewed	Open access	2018	Health care		Informed general terminology, search strategy, articulating outcome measures

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Nilsen (259)	Peer-reviewed	Open access	2006	Health care		Informed general terminology, informed search strategy
Tackling Representativeness: A Roadmap and Rubric (260)	Not peer-reviewed	Publicly accessible website	2018	Health care	Tackling Representativeness: A Roadmap and Rubric	Informed terminology around representation
The Value of Engagement (PCORI) (261)	Not peer-reviewed	Publicly accessible website	2018	Health care		Informed general terminology, concepts of 'engagement' and 'involvement' and partnerships and evidence informed involvement
Abma(262)	Peer-reviewed	Open access	2018	Health care and health research		Informed terminology to describe codesign in healthcare and health research context, including 'agenda setting' and prioritisation, power and 'knowledge hierarchies'
Carman(263)	Peer-reviewed	Open access	2013	Health care, population health	A framework for understanding the elements and developing	Informed general terminology, including different descriptions of involvement and enabling conditions that support it

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					interventions and policies	
Guide to producing and sourcing quality health information, Cochrane Consumers and Communication(264)	Not peer reviewed	Open access	2019	Health information production	Guide to Producing and Sourcing Quality Health Information	Informed terminology to describe co-production of health information and outcome measures
John. E Ware(265)	peer-reviewed	Open access	1992	Health outcomes	The MOS 36-Item Short-Form Health Survey (SF-36)	
Stakeholder Engagement Framework, Australian Government(266)	Not peer-reviewed	Publicly accessible website	2017	Health policy	Stakeholder Engagement Framework (Australian Government)	Informed terminology and involvement planning
Barriers to community involvement in health and medical research, University of Western Australia(267)	Not peer-reviewed	Publicly accessible website	2016	Health Research		Influenced terminology around barriers to involvement in research
Dillon(168)	Peer-reviewed	Open access	2017	Health research		Informed terminology defining stages of research, outcomes and indicators of involvement
EQUATOR reporting guidelines(268)	Not peer-reviewed	Publicly accessible website	2019	Health research	EQUATOR reporting guidelines	Informed general terminology, informed design of reporting 'explicit

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						methodology', STARDIT designed to work with all EQUATOR guidelines.
How to develop a reporting guideline, The EQUATOR Network(92)	Not peer-reviewed	Publicly accessible website	2018	Health research	How to develop a reporting guideline, EQUATOR	Informed general terminology, informed the design of the process for co-creating STARDIT
Kaisler(269)	Not peer-reviewed (pre-print)	Open access	2019	Health research	Patient and public involvement and engagement in research - a "how to" guide for researchers	Informed terminology to describe involving people in health research and assessing involvement
Moher(87)	Peer-reviewed	Open access	2010	Health research	EQUATOR method for developing reporting guidelines	Informed general terminology, informed the design of the process for co-creating STARDIT
National Standards for Public Involvement in Research (UK) (115)	Not peer-reviewed	Publicly accessible website	2018	Health research	National Standards for Public Involvement in Research (UK)	General terminology, indicators of involvement (including impact)
NIHR Public Involvement Impact Working Group (270)	Not peer-reviewed	Publicly accessible website	2019	Health research		Informed definitions of impact

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Patient and Public Involvement and Engagement Plan, NIHR Central Commissioning Facility(271)	Not peer-reviewed	Open access	2019	Health Research		Informed terminology to describe people involved in health research
Patient engagement (Canadian Institutes of Health Research) (272)	Not peer-reviewed	Publicly accessible website	2017	Health research		Informed general terminology around involving people in health research
Public Involvement (Health Research Authority) (63)	Not peer-reviewed	Publicly accessible website	2019	Health research		Informed general terminology, including distinctions between involvement and engagement
Public Involvement Impact Assessment Framework (110)	Not peer-reviewed	Publicly accessible website	2014	Health research	Public Involvement Impact Assessment Framework (PiiAF)	General terminology, mapping values and preferences associated with involvement, assessing impacts of involvement
Staniszewska(273)	Peer-reviewed	Open access	2017	Health research	GRIPP2 reporting checklists: tools to improve reporting 832 of patient and public involvement in research	Informed terminology, ways of reporting involvement and impact, mapping preferences for involvement
Strategy for Patient-Oriented Research (SPOR), Canadian	Not peer-reviewed	Publicly accessible website	2015	Health research		Informed general terminology, including describing outcomes of

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Institutes of Health Research(274)						involvement, and involvement in governance
Tong(275)	Peer-reviewed	Open access	2019	Health research (priority setting)	Reporting guideline for priority setting of health research (REPRISE)	Informed terminology for reporting of priority setting of health research
Workbook to guide the development of a Patient Engagement in Research (PEIR) Plan, University of British Columbia (276)	Not peer- reviewed	Publicly accessible website	2018	Health Research		Influenced terminology to describe partnership working
Wright(277)	Peer-reviewed	Open access	2010	Health research	Critical appraisal guidelines for assessing the quality and impact of user involvement in research.	Informed general terminology, including appraising involvement in research by assessing the quality and impact of involvement
Establishing and Sustaining meaningful Patient and Public Involvement and Engagement in Research in Sri Lanka, Institute for Research and Development (Sri Lanka)(278)	Not-peer reviewed	Publicly accessible website	2018	Health research (ethics)		Informed terminology to describe involving people in ethical review of research
Claw(279)	Peer-reviewed	Open access	2018	Health research (genomic research in	A framework for enhancing ethical	

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
				Indigenous communities)	genomic research with Indigenous communities	
Viergever(280)	Peer-reviewed	Open access	2010	Health research (priority setting)		
Concannon(281)	Peer-reviewed	Paywall access	2012	Health research and policy		General terminology, taxonomy for stages of research adapted from this model
The Value+ Toolkit (European Patients' forum) (119)	Not peer-reviewed	Publicly accessible website	2013	Health research and services	The Value+ Toolkit (European Patients' forum)	Informed general terminology, informed definitions of involvement and indicators of involvement and barriers to involvement. STARDIT designed to align with Value+ Toolkit
Cochrane Knowledge Translation Strategy(282)	Not peer-reviewed	Publicly accessible website	2017	Health research evidence, knowledge translation		General terminology, including 'audiences' and ways of assessing knowledge translation
Tugwell(283)	Peer-reviewed	Open access	2006	Health research evidence, knowledge translation	Cascade for equity-oriented knowledge translation (6ps)	General terminology, labels for multiple stakeholders, ways of assessing facilitators and barriers (including 'community' involvement),

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						ways of involving people in co-designing research, ways of assessing equity-oriented knowledge translation
VCCC Toolkit, Victorian Comprehensive Cancer Centre, Melbourne, Australia(284)	Not peer reviewed	Publicly accessible website	2019	Health services and research		Informed terminology specific to involving people in Australian healthcare
A Guide for Patient Group Partners, Scottish Medicines Consortium(285)	Not peer-reviewed	Open Access	2017	Health technology assessment		Informed terminology to describe people involved in health technology processes, and data which informs the assessment process
European Network for Health Technology Assessment(286)	not peer-reviewed	Public domain		Health technology assessment (methodological framework)	HTA Core Model	
Fredriksson(287)	Peer-reviewed	Paywall access	2016	Healthcare		Informed general terminology
Ogrinc(288)	Peer-reviewed	Open Access	2016	Healthcare	Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)	Informed terminology to describe reporting of knowledge to improve healthcare

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Partnering in healthcare; A framework for better care and outcomes (289)	Not peer-reviewed	Publicly accessible website	2019	Healthcare	Development of a Patient Engagement In Research (PEIR) Plan	Influenced terminology to describe involving people in improving healthcare services
The Innovation Imperative: The Future of Drug Development, The Economist Intelligence Unit(290)	Not peer-reviewed	Publicly accessible website	2018	Healthcare		Informed general terminology including involving patients in the design and management of both clinical trials and precision medicine
SPIRIT 2013 Checklist	Peer-reviewed	Public domain	2013	Healthcare (clinical trial protocols)	Standard protocol items: recommendations for interventional trials (SPIRIT 2013 Checklist)	
Moullin(291)	Peer-reviewed	Open Access	2015	Healthcare (implementation science and frameworks, knowledge translation)	Generic Implementation Framework (GIF)	Informed terminology to describe implementation framework types, including the variations in terminology to describe implementation frameworks.
Domecq(292)	Peer-reviewed	Open access	2014	Healthcare research		Informed general terminology, informed search strategy

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Patient-Centered Outcomes Research Institute definition of 'Stakeholders'(293)	Not peer-reviewed	Publicly accessible website	2018	Healthcare research		Informed general terminology within the word 'stakeholder'
Planning for Consumer and Community Participation in Heath and Medical Research, University of Western Australia(294)	Not peer reviewed	Open access	2014	Heath Research		Informed terminology to describe people involved in research
Impact in Participatory Health Research, International Collaboration for Participatory Health Research(69)	Not-peer reviewed	Publicly accessible website	2020	Heath research (participatory)		Informed terminology to describe impact from participatory health research
MedWatch, Food and Drug Administration (USA)(295)	Not peer-reviewed	Public domain		Human Medical Products (Safety Alerts)		
Association for the Accreditation of Human Research Protection Programs, Inc (AAHRPP)(296)	Not-peer reviewed	Publicly accessible website	2018	Human research ethics (accreditation)	Association for the Accreditation of Human Research Protection Programs Standard I-9	Influenced language to describe standardised accreditation of human research ethics processes
Report of operations, Voluntary Assisted Dying Review Board, Safer Care Victoria(297)	Not-peer reviewed	Publicly accessible website	2019	Independent monitoring and		Informed ways of explaining ethical data redaction and

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
				reviewing (voluntary assisted dying)		reporting oversight of voluntary assisted dying
CARE Principles for Indigenous Data Governance, Global Indigenous Data Alliance(298)	Not peer-reviewed	Public domain		Indigenous context to open data access	CARE Principles for Indigenous Data Governance	
The World Factbook, Central Intelligence Agency (USA)(299)	Not peer-reviewed	Open Access	2020	Intelligence (USA Government)		Informed methods for reporting standardised data about planet Earth. Informed terminology to describe the 'intelligence cycle', including the data types 'basic', 'current' and 'estimative'.
Fazey (132)	Peer-reviewed	Paywall access	2014	Interdisciplinary and multi-stakeholder research		Informed terminology regarding knowledge exchange in interdisciplinary and multi-stakeholder research
Code of Conduct for Evaluation in the UN system (United Nations Evaluation Group)(300)	Not peer-reviewed	Publicly accessible website	2008	Inter-disciplinary evaluation	Code of Conduct for Evaluation in the UN system (United Nations Evaluation Group)	Informed general terminology, including evaluation
Detail of Impact Evaluation Guidance Document (United Nations Evaluation Group)(49)	Not peer-reviewed	Publicly accessible website	2013	Inter-disciplinary evaluation	Detail of Impact Evaluation Guidance Document (United	Informed general terminology, including evaluation of impact,

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					Nations Evaluation Group)	indicators of impact and concepts of 'validity' and 'transparency'
Good Practice Guidelines for Follow up to Evaluations (United Nations Evaluation Group)(301)	Not peer-reviewed	Publicly accessible website	2010	Inter-disciplinary evaluation	Good Practice Guidelines for Follow up to Evaluations (United Nations Evaluation Group)	Informed general terminology, including evaluation
Guidance on Evaluating Institutional Gender Mainstreaming (United Nations Evaluation Group)(302)	Not peer-reviewed	Publicly accessible website	2018	Inter-disciplinary evaluation	Guidance on Evaluating Institutional Gender Mainstreaming (United Nations Evaluation Group)	Informed general terminology, including evaluation
Mapping & Review of Evaluation Ethics (United Nations Evaluation Group)(303)	Not peer-reviewed	Publicly accessible website	2019	Inter-disciplinary evaluation		Informed general terminology, including evaluation
Norms and Standards for Evaluation (United Nations Evaluation Group)(304)	Not peer-reviewed	Publicly accessible website	2016	Inter-disciplinary evaluation	Norms and Standards for Evaluation (United Nations Evaluation Group)	Informed general terminology, including evaluation and indicators of impact

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Quality Checklist for Evaluation Reports (United Nations Evaluation Group)(305)	Not peer-reviewed	Publicly accessible website	2010	Inter-disciplinary evaluation	Quality Checklist for Evaluation Reports (United Nations Evaluation Group)	Informed general terminology, including evaluation
Quality Checklist for Evaluation Terms of Reference and Inception Reports (United Nations Evaluation Group)(306)	Not peer-reviewed	Publicly accessible website	2010	Inter-disciplinary evaluation	Quality Checklist for Evaluation Terms of Reference and Inception Reports (United Nations Evaluation Group)	Informed general terminology, including evaluation
Professional Peer Review Of The UNESCO Evaluation Function (United Nations Evaluation Group)(307)	Professional peer review	Publicly accessible website	2020	Inter-disciplinary evaluation of evaluation methodology		Informed terminology to describe methods of evaluating evaluation methodologies
Wilsdon(308)	Published book	Paywall access	2015	Inter-disciplinary evaluation of metrics and indicators		Informed terminology to describe the scope and uses and limitations of research metrics and indicators.
Glossary of Key Terms in Evaluation and Results Based Management, Organisation for	Not-peer reviewed	Publicly accessible website	2002	International development		Informed terminology around impact and evaluation, informed methods of parallel

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Economic Co-operation and Development (OECD)(309)						definitions in multiple languages
International Aid Transparency Initiative (IATI) Standard(310)	Not-peer reviewed	Publicly accessible website	2019	International development	International Aid Transparency Initiative (IATI) Standard	Informed terminology for data reporting for international aid and development, informed terminology to describe methods of reporting and sharing data
Broadening The Range Of Designs And Methods For Impact Evaluation, Department for International Development (UK)(311)	Not-peer reviewed	Publicly accessible website	2012	International development (evaluation)		Informed terminology to describe impact and evaluation methodology and causal inference and terminology to describe theory of change
Impact Evaluation Glossary, International Initiative for Impact Evaluation (3ie)(312)	Not-peer reviewed	Publicly accessible website	2012	International development (evaluation)		Informed terminology to describe impact and evaluation methodology
Mansuri(313)	Peer reviewed	Publicly accessible website	2004	International development (evaluation)		Informed terminology to describe concepts such as 'community driven' and 'social capital'
Olken(314)	Peer-reviewed	Paywall access	2007	International development (evaluation)		Informed terminology to describe and report concepts

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						such as 'corruption', 'auditing' and conflicting interests
The Social Impact of Social Funds in Jamaica: A Mixed-Methods Analysis of Participation, Targeting and Collective Action in Community Driven Development, The World Bank(315)	Not-peer reviewed	Publicly accessible website	2003	International development (evaluation)		Informed terminology for reporting participation and concepts such as 'collective action' and 'community driven'
Woolcock(316)	Peer-reviewed	Paywall access	2008	International development (evaluation)		Informed terminology for reporting methods of reporting impact, including long-term impact trajectories
Gibson(316)	Peer-reviewed	Paywall access	2008	International development (participatory projects)		Informed terminology for reporting concepts such as 'empowerment', 'inequity' and 'social legitimacy'
Hentschel(317)	Peer-reviewed	Paywall access	1999	International development (primary healthcare)		Informed terminology to describe reporting methodology for evaluating international development in primary healthcare
Social Determinants of Health (World Health Organization) (318)	Published book (WHO)	Open access	2003	International public health		Informed 'Other information' in describing authors categories and 'barriers'

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						(describing potential equity issues for who was involved)
Cheer(319)	Peer-reviewed	Open Access	2020	Involvement in research (environment, health and wellbeing)	Know the Risk, Own the Risk, Flip the Risk framework	Informed language to describe interdisciplinary involvement of people in research (specifically Torres Strait Islanders)
Public Interest Journalism Initiative(320)	Not peer-reviewed	Open Access	2020	Journalism		Informed terminology to describe public interest journalism principles, including defining 'public interest' and 'plurality'
Pinnock(321)	Peer-reviewed	Open Access	2017	Knowledge translation (implementation science)	Standards for Reporting Implementation Studies (StaRI) Statement	
Current Good Manufacturing Practice in Manufacturing, Packaging, Labelling, or Holding Operations for Dietary Supplements, Center for Food Safety and Applied Nutrition(322)	Not peer-reviewed	Public domain	2018	Manufacturing (Good Manufacturing Practice)	Small Entity Compliance Guide: Current Good Manufacturing Practice in Manufacturing, Packaging, Labelling, or Holding Operations for	

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					Dietary Supplements	
Therapeutic Goods Administration, Department of Health, Australian Government(323)	Not peer-reviewed	Public domain	2018	Manufacturing (principles for medicinal products)	Good Manufacturing Practice (GMP), Australia	
Rison(149)	Peer-reviewed	Open Access	2013	Medical Case Reports	CARE (CAse REport) guidelines and the standardization of case reports	Informed terminology for standardised creating standardised descriptions, including of medical case reports
International Committee of Medical Journal Editors (defining the role of authors and contributors) (324)	Not peer-reviewed	Publicly accessible website	2019	Medical journal publication		Informed terminology defining 'authorship', including authors of STARDIT reports
ISBT 128 Standard, International Council for Commonality in Blood Banking Automation(325)	Global standard for the identification, labelling, and information transfer of medical products of human origin	Open Access	2018	Medical products of human origin	ISBT 128 Standard	Informed definitions for standard identification, labelling, and information transfer of medical products of human origin
Uniform requirements for manuscripts submitted to biomedical journals: Writing and	Peer-reviewed	Open Access	2010	Medical publishing	Uniform requirements for manuscripts	Informed terminology to describe articles submitted to medical journals

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
editing for biomedical publication, International Committee Of Medical Journal Editors(326)					submitted to biomedical journals: Writing and editing for biomedical publication	
World Association of Medical Editors (WAME)(327)	Not-peer reviewed	Publicly accessible website	2020	Medical publishing		Informed general terminology including quality assurance in medicine
Guidelines for reporting patient and public involvement in research, British Medical Journal(328)	Not peer-reviewed	Publicly accessible website	2019	Medical research	Guidelines for reporting patient and public involvement in research, British Medical Journal	Informed minimum reporting requirements for STARDIT, informed 'cost' and 'time' reporting
The SPIRIT Statement(329)	Not peer-reviewed	Open Access	2020	Medical trial protocols	SPIRIT	Informed terminology to describe trial protocols
Therapeutic Goods Administration (TGA), Australian Government Department of Health(330)	Not peer-reviewed	Public domain	2019	Medicine and pharmaceutical manufacturing		Informed terminology to describe good manufacturing process clearance process
Dubois(331)	Peer-reviewed	Open access	2013	Medicine comparative effectiveness research	Framework for understanding the pace of evidence adoption	Informed terminology around involving people in assessing evidence adoption

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Patient Engagement Quality Guidance (109)	Not peer-reviewed	Publicly accessible website	2018	Medicine development		Informed general terminology, including assessing involvement in the stages of medicine development
The book of good practices in Patient Engagement (332)	Not peer-reviewed	Publicly accessible website	2018	Medicine development		Informed general terminology, including defining stakeholders and stages of medicine development
Spindler(333)	Peer-reviewed	Open access	2018	Medicine research and development	European Patients Academy on Therapeutic Innovation (EUPATI) Guidelines on Patient Involvement in Research and Development	Informed general terminology, including stages aligned to guidelines
Patient Focused Medicines Development (PFMD) 'Book of Good Practices' (334)	Not peer-reviewed	Publicly accessible website	2018	Medicines research		Informed general terminology, terminology around shared 'purpose' and data collection fields – in particular the 'Patient Engagement Quality Guidance Tool' ('Planning a project' and

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						'Assessing an ongoing or completed project')
Research Priorities for Children and Young People's Mental Health: Interventions and Services, McPin Foundation(335)	Not peer-reviewed	Open access	2018	Mental health		Informed terminology to describe people involved and terminology for governance
Ennis(336)	Peer-reviewed	Open access	2018	Mental health research		Informed general terminology, including language to describe longitudinal impact of involvement.
France(337)	Peer-reviewed	Open Access	2019	Meta-ethnography reporting	Meta-ethnography Reporting Guidance (eMERGe)	Informed terminology to describe the reporting the synthesis process of meta-ethnography
Military Expenditure Database, Stockholm International Peace Research Institute (SIPRI)(338)	Not peer-reviewed	Public domain	2021	Military Expenditure		
Arms Industry Database, Stockholm International Peace Research Institute (SIPRI)(339)	Not peer-reviewed	Public domain	2021	Military, weapons and arms		

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Arms Transfers Database, Stockholm International Peace Research Institute (SIPRI)(340)	Not peer-reviewed	Public domain	2021	Military, weapons and arms		
Multilateral Peace Operations Database, Stockholm International Peace Research Institute (SIPRI)(341)	Not peer-reviewed	Public domain	2021	Multilateral peace operations		
Center for Open Science(342)	Not-peer reviewed	Publicly accessible website	2020	Open Science		Informed terminology, including concepts such as 'openness', 'integrity' and 'reproducibility'
Haddaway(343)	Peer-reviewed	Open access	2018	Open science		Informed terminology for evidence synthesis across disciplines
Indicator Frameworks for Fostering Open Knowledge Practices in Science and Scholarship, European Union(344)	Not-peer reviewed	Publicly accessible website	2019	Open Science	Indicator Frameworks for Fostering Open Knowledge Practices in Science and Scholarship (European Union)	Informed terminology to describe indicators of open science and other related terminology for assessing open knowledge practices
Open Science Manifesto(345)	Not peer-reviewed	Publicly accessible website		Open Science	Open Science Manifesto	Informed terminology for open science and describing values such as 'inclusive'

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Open science monitor(346)	Not peer-reviewed	Publicly accessible website	2020	Open science		Informed terminology to describe open scientific collaboration, including application program interfaces (APIs)
Zooniverse(347)	Not-peer reviewed	Publicly accessible website	2020	Open Science		Informed terminology to describe people involved in research, data sharing and other governance
Todd(348)	Peer-reviewed	Open access	2019	Open Science, drug discovery	Six Laws of Open Source Drug Discovery	Informed terminology to describe open science, including governance and data ownership
Patient Engagement Monitoring and Evaluation Framework with metrics, Paradigm(349)	Peer-reviewed	Public domain	2020	Patient engagement in healthcare and medicine development		Informed terminology to describe monitoring and evaluation of patient engagement
Esmail(350)	Peer-reviewed	Open access	2015	Patient engagement research	Evaluating patient and stakeholder engagement in research	Informed general terminology, including evaluating the impact of involvement
Dawn, P. Richards(272)	Peer-reviewed	Open-access	2020	Patient-orientated research in chronic pain	CIHR Strategy for Patient-Oriented Research - Patient	

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					Engagement Framework	
OpenID Self-Certification, OpenID Foundation(351)	Not-peer reviewed	Publicly accessible website	2015	Personal identification (identity verification)		Informed terminology to describe self-certification and identify verification
Parker(352)	Peer-reviewed	Open access	2019	Pharmaceuticals		Informed terminology and reporting of competing or conflicting interests.
Test, Learn, Adapt: Developing Public Policy with Randomised Controlled Trials(353)	Not peer-reviewed	Publicly accessible website	2012	Policy		Informed terminology and methodology for measuring the impact of policy
The Rise of Experimental Government, What Works UK(354)	Not-peer reviewed	Publicly accessible website	2018	Policy		Informed terminology to describe standardised reporting in government policy, including randomised controlled trials
Using research evidence: A Practice Guide, Nesta(355)	Not-peer reviewed	Publicly accessible website	2016	Policy		Informed terminology to describe reporting and using evidence in policy (in particular social policy), informed alternative methods of evaluation used for evidence-informed decision making

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Gaudet(356)	Published book chapter	Open Access	2015	Policy (science and evaluation)	Model of knowledge and ignorance mobilization dynamics in science	Informed definitions of ignorance and knowledge, including concepts of 'ignorance mobilisation'
Wild(357)	Peer-reviewed	Open access	2005	Principles of good practice for patient-reported outcomes	Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes	
Product Safety Australia, Australian Competition and Consumer Commission(358)	Not-peer reviewed	Publicly accessible website	2020	Product safety	Mandatory and voluntary information standards	Informed language about for reporting voluntary safety standards.
Michie(359)	Peer-reviewed	Open access	2011	Public health (evidence-based behaviour change)	The COM-B system - a framework for understanding Behaviour	Informed terminology to describe differences between interventions and policy, including definitions of education, incentivisation, coercion and enablement.
Nunn(8)	Peer-reviewed	Open access	2019	Public health genomics		Informed general terminology, informed task-based reporting categories.

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
EAST: Four simple ways to apply behavioural insights, The Behavioural Insights Team(360)	Not peer-reviewed	Publicly accessible website	2014	Public policy (behaviour change)	EAST: Four simple ways to apply behavioural insights	Defining and measuring outcomes of initiatives and policy
Kneebone(361)	Peer-reviewed	Paywall access	2016	Public policy (behaviour change)	The impact-likelihood matrix: a policy tool for behaviour prioritisation	Informed terminology for describing and measuring outcomes of interventions to change behaviours
The BehaviourWorks Method(118)	Not peer-reviewed	Publicly accessible website	2019	Public policy (behaviour change)		Informed terminology to describe involving people in identifying problems and outcome measures
Crossref(362)	Not-peer reviewed	Publicly accessible website	2020	Publication and data sharing		Informed terminology to describe references and standardising research outputs
Committee on Publication Ethics (COPE)(363)	Not-peer reviewed	Publicly accessible website	2015	Publication ethics		Informed terminology, including to describe guidelines and standards
Guidance for Editors: research, audit and service evaluations, Committee on Publication Ethics (COPE)(364)	Not-peer reviewed	Publicly accessible website	2014	Publication ethics	Guidance for Editors: research, audit and service evaluations, Committee on	Informed terminology to describe the variation of international ethical standards

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
					Publication Ethics (COPE)	
Principles of Transparency and Best Practice in Scholarly Publishing, Committee on Publication Ethics (COPE)(365)	Not-peer reviewed	Publicly accessible website	2014	Publication ethics	Principles of Transparency and Best Practice in Scholarly Publishing, Committee on Publication Ethics (COPE)	Informed terminology, including concepts of ethical transparency
O'Brien(366)	Peer-reviewed	Open access	2014	Qualitative research	Standards for Reporting Qualitative Research (SRQR)	Informed checklist creation and principles for reporting guidelines
Tong(367)	Peer-reviewed	Open access	2007	Qualitative research	Consolidated criteria for reporting qualitative research (COREQ)	Informed checklist creation and principles for reporting guidelines
Schulz(368)	Peer-reviewed	Open access	2010	Randomised controlled trials	CONSORT for randomised controlled trials	General terminology, including stages of trials, outcome reporting and other categories.
DELWP Output Data Standards (369)	Not peer-reviewed	Open access	2015	Reporting standards		Informed terminology and methodology for monitoring,

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
						evaluation and reporting of environmental initiatives
Research Activity Identifier (RAiD)(370)	Not peer-reviewed	Publicly accessible website	2018	Research (multi-disciplinary)		STARDIT designed to be interoperable with RAiD
Engagement and Impact Assessment, Australian Research Council(120)	Not peer-reviewed	Publicly accessible website	2018	Research (multi-disciplinary)*	Engagement and Impact Assessment (Australian Research Council)	Informed general terminology, including assessing involvement and impact
Partnering with Consumers Standards, Australian Commission on Safety and Quality in Health Care(371)	Not peer-reviewed	Publicly accessible website	2011	Safety and Quality in Health Care	Partnering with Consumers Standards, Australian Commission on Safety and Quality in Health Care	Informed general terminology and informed reporting of involvement.
Wilkinson(127)	Peer-reviewed	Open access	2016	Scholarly data (multi-disciplinary)	FAIR Guiding Principles for scientific data management and stewardship	Alignment with categories for reporting on principles for scientific data
Open Toolkit for Tracking Open Science Partnership Implementation and Impact(372)	Not peer-reviewed	Open access	2019	Science (multi-disciplinary)		Informed terminology and data collection fields

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Directory of Open Access Journals(373)	Not-peer reviewed	Publicly accessible website	2020	Scientific publishing		Informed terminology to described metadata and independence
European Association of Science Editors(374)	Not peer-reviewed	Publicly accessible website	2019	Scientific publishing	Guidelines for Authors and Translators of Scientific Articles to be Published in English (European Association of Science Editors)	Informed terminology, in particular the concept of avoiding 'empty words and sentences' and correct use of scientific terms
Open Access Scholarly Publishers Association(375)	Not-peer reviewed	Publicly accessible website	2020	Scientific publishing		Informed terminology to describe integrity and stakeholder collaboration
Promoting Integrity in Scientific Journal Publications, Council of Science Editors (376)	White paper	Publicly accessible website	2018	Scientific publishing		Informed terminology including concepts of confidentiality, conflict of interest, authorship and contribution models such as 'contributorship'
Scientific style and format, Council of Science Editors(377)	Published book	Paywall access	2014	Scientific publishing		
WikiJournal User Group Ethics Statement(378)	Not-peer reviewed	Publicly accessible website	2020	Scientific publishing		Informed general terminology and development of core ethical principles

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Participation in Scientific Research (PPSR) Core metadata standards repository, Citizen Science Association (USA)(379)	Public Domain	Open Access	2020	Scientific Research (public participation)	Participation in Scientific Research (PPSR) Core metadata standards repository	Informed terminology to describe concepts such as 'public participation in scientific research'
Tricco(380)	Peer-reviewed	Open access	2018	Scoping reviews	PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation	Informed terminology, including standardised reporting of scoping reviews methodology
Assessing the Impacts of Social and Environmental Standards Systems(381)	Not-peer reviewed	Publicly accessible website	2014	Social and Environmental (data standards)	Assessing the Impacts of Social and Environmental Standards Systems	Informed terminology for assessing impacts of standardised data
International Social and Environmental Accreditation and Labelling Alliance(382)	Not-peer reviewed	Publicly accessible website	2020	Social and Environmental (data standards)		Informed terminology to describe international multi-disciplinary sustainability standards, including concepts of 'credibility'
Co-production in social care: What it is and how to do it, Social Care Institute for Excellence(383)	Not-peer reviewed	Publicly accessible website	2015	Social care		Informed terminology to describe co-production in the context of social care

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Brazma(384)	Peer-reviewed	Open access	2001	Standard for recording and reporting microarray-based gene expression data	Minimum information about a microarray experiment (MIAME)	Informed standardised reporting of a form of genetic data (microarray-based gene expression data)
Information and Data Standard for Sustainability, Forest Stewardship Council and International Social and Environmental Accreditation and Labelling Alliance(385)	Not-peer reviewed	Publicly accessible website	2020	Sustainability (data standard)	Information and Data Standard for Sustainability	Informed terminology to describe standardised data 'sustainability'
Tong(386)	Peer-reviewed	Open Access	2012	Synthesis of qualitative research	Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ)	Informed terminology for reporting the synthesis of qualitative research
Wong(387)	Peer-reviewed	Open Access	2013	Systematic review method (Realist And Meta-narrative Evidence Syntheses)	RAMESES (Realist And MEta-narrative Evidence Syntheses: Evolving Standards)	Informed terminology for reporting realist and meta-narrative evidence syntheses
Wong(388)	Peer-reviewed	Open Access	2016	Systematic review method (Realist And Meta-narrative Evidence Syntheses)	RAMESES II (Realist And MEta-narrative Evidence Syntheses: Evolving Standards)	Informed terminology for reporting realist and meta-narrative evidence syntheses

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Moher(131)	Peer-reviewed	Open access	2009	Systematic Reviews	Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement	General terminology, including stages of systematic reviews
Pollock(389)	Peer-reviewed	Paywall access	2019	Systematic reviews in health research	ACTIVE framework to describe stakeholder involvement in systematic reviews	Informed terminology around defining stakeholders and ways of defining involvement
Pollock(390)	Peer-reviewed	Open access	2018	Systematic reviews in health research		Informed general terminology, informed design of STARDIT creation process
PROGRESS-Plus, Cochrane(391)	Not peer-reviewed	Publicly accessible website	2017	Systematic reviews in health research	PROGRESS-Plus (Cochrane)	Informed 'Other information' in describing authors categories and 'barriers' (describing potential equity issues for who was involved)
Checklist of CITES Species, Convention on International Trade in Endangered Species of Wild Fauna and Flora(392)	Multilateral treaty	Open Access	1975	Trade in Endangered Species of Wild Fauna and Flora	Checklist of CITES Species (Convention on International Trade in Endangered Species of Wild Fauna and Flora)	Informed design of structured data to describe species

Name	Status	Access	Year	Field	Reporting standard, guideline or taxonomy	Aspects which informed STARDIT
Inglehart(393)	Peer-reviewed	Paywall access	2006	Values and beliefs		Informed terminology for describing methods of mapping people's 'values' and other associated beliefs and perspectives

The following URLs were discovered during the public consultation search phase and will be added to the final version of Table 5, referenced in the same way:

- <https://globalfungi.com/>
- https://www.banktrack.org/page/about_banktrack
- <https://eol.org/>
- <https://fsc.org/en/newsfeed/fscr-launches-new-global-brand-forests-for-all-forever>
- <https://cstrack.eu/>
- <https://bettercotton.org/>
- [George Church's Personal Genomes Project](#)
- Data Use Ontology (DUO) technical standard (<https://github.com/EBISPOT/DUO>), which is a series of data access codes that can be applied to research cohort datasets to describe data access and use permissions in machine-readable formats.
- <https://geoblacklight.org/> A multi-institutional open-source collaboration building a better way to find and share geospatial data
- https://www.citizenscience.org/2015/10/09/ppsr_core-metadata-standard/
- Schemas
 - DCMS
 - Schema.org

- GBL
- DCAT
- https://www.wikidata.org/wiki/Wikidata:Property_proposal/PeriodO_period_ID
- Dublincore: <https://dublincore.org/>
- <https://www.dublincore.org/specifications/dublin-core/dcmi-terms/>
- <https://www.planetaryhealthalliance.org/planetary-health>
- SciStarter [global citsci project finder]: <https://scistarter.org/>
- Australian project finder: <https://citizenscience.org.au/ala-project-finder/> [I helped facilitate SciStarter & ALA developing an API]
- The EU Citizen Science Cost Action CA15212 [<https://cs-eu.net/>] and it's working group on Interoperability Working Group [<https://cs-eu.net/wgs/wg5/>]; The working group's outputs are reports [<https://cs-eu.net/wgs/wg5/resources>] and for context, I contributed to the workshop in Geneva and subsequent report "On the citizen-science ontology, standards & data [<https://cs-eu.net/news/workshop-report-wg-5-geneva-declaration-citizen-science-data-and-metadata-standards>]. The initiative recently rapped up and an associated book was published [<https://cs-eu.net/news/book-science-citizen-science>]. Several chapters may be of interest but around data and metadata efforts for citsci, see the chapter led by Rob Lemmens. I am currently working with him, Xeni, and Ina to progress some testing of the standards based on existing projects (included Jack in an email including them and Luigi as the COST Action working group).
- There is also a citizen science community of practice on data interoperability that is ending this month through the EU initiative, WeObserve. There is a lot of overlap in people with the COST Action group. See the resources created on their page: <https://www.weobserve.eu/weobserve-cop3-interoperability-and-standards-for-citizen-observatories/>
- From the US there is the CSA Data and Metadata working group [be sure and see overhead tabs too: <https://www.citizenscience.org/get-involved/working-groups/data-and-metadata-working-group/>], and a subset of that group, including myself has been exploring development of the PPSR Core standards. I also CCed Greg Newman as chair of that group and Brandon Budnicki who is largely responsible for pulling all of our years discussions to date into creating the publicly accessible website very recently with ability to contribute via GitHub. PPSR Core: A Data Standard for Public Participation in Scientific Research (Citizen Science) [<https://core.citizenscience.org/>]
- Australian Government. Dept of Education, Skills and Employment. Foundation Skills for Your Future Program. Digital Literacy Skills Framework. APRIL 2020. https://docs employment.gov.au/system/files/doc/other/digital_literacy_skills_framework_accessible.pdf
- Australian Healthcare and Hospitals Association (AHHA) – Experience Based Co-design Toolkit: <https://ahha.asn.au/experience-based-co-design-toolkit#:~:text=The%20Experience%20Based%20Co%2DDesign,to%20deliver%20an%20improved%20experience.>
- Diener, E., Wirtz, D., Tov, W., Kim-Prieto, C., Choi, D., Oishi, S., & Biswas-Diener, R. (2009). New measures of well-being: Flourishing and positive and negative feelings. *Social Indicators Research*, 39,247-266.

- Grant and Booth (2009) - A typology of reviews: an analysis of 14 review types and associated methodologies. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>
- Greenhalgh T, Wherton J, Papoutsis C, Lynch J, Hughes G, A'Court C, Hinder S, Fahy N, Procter R, Shaw S
- Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies
- J Med Internet Res 2017;19(11):e367. URL: <https://www.jmir.org/2017/11/e367>. DOI: 10.2196/jmir.8775
- IAP2. Pillars of Public Participation. <https://www.iap2.org/page/pillars>
- KUKUTAI, T., & TAYLOR, J. (Eds.). (2016). Indigenous Data Sovereignty: Toward an agenda. Acton ACT, Australia: ANU Press. Retrieved March 25, 2021, from <http://www.jstor.org/stable/j.ctt1q1crgf>
- Moher D, Bouter L, Kleinert S, Glasziou P, Sham MH, Barbour V, et al. (2020) The Hong Kong Principles for assessing researchers: Fostering research integrity. PLoS Biol 18(7): e3000737. <https://doi.org/10.1371/journal.pbio.3000737>
- Peterson, A., Charles, V., Yeung, D., & Coyle, K. (2020). The Health Equity Framework: A Science- and Justice-Based Model for Public Health Researchers and Practitioners. Health Promotion Practice. <https://doi.org/10.1177/1524839920950730>
- Spiers, H., Swanson, A., Fortson, L., Simmons, B. D., Trouille, L., Blickhan, S. and Lintott, C. (2019). 'Everyone counts? Design considerations in online citizen science'. JCOM 18 (01), A04. <https://doi.org/10.22323/2.18010204>.
- The Point of Care Foundation. EBCD: Experience-based Co-design Toolkit. <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>
- Walter, M., Kukutai, T., Carroll, S.R., & Rodriguez-Lonebear, D. (Eds.). (2020). Indigenous Data Sovereignty and Policy (1st ed.). Routledge. <https://doi.org/10.4324/9780429273957>
- Understanding Participation: The 'citizen science' of genetics
https://www.researchgate.net/publication/236850804_Prairnsack_B_Understanding_Participation_The_'citizen_science'_of_genetics_In_Prairnsack_B_Werner-Felmayer_G_Schicktan_S_eds_Genetics_as_Social_Practice_Farnham_Ashgate/stats
- Open trials: <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-016-1290-8>

eDNA reporting

- <https://metadatalogue.lifewatch.eu/srv/eng/catalog.search#/metadata/55dfbb63-4304-4fa8-a7b6-17988e0b33df>
- <http://dnabarcoding101.org/>
- There is a within environment discipline example, albeit on a regional scale. The guiding principles of iCLIM (a Griffith Uni & SPREP

managed project) is attempting to standardise the sharing of project and climate information for the Pacific. As to how standardised, open and effective it actually is for people needing information I am not sure. I was part of an advisory board for traditional knowledge aspects of its design in its early stages, but haven't been involved for a while. I can put you in touch with the relevant people developing and managing iCLIM if you are interested. More about its design here: <https://www.griffith.edu.au/research/research-excellence/griffith-climate-change-response-program/pacific-iclim/about-pacific-iclim>

- <https://www.cisac.org/about> “CISAC – the International Confederation of Societies of Authors and Composers – is the world’s leading network of authors’ societies” – informed terminology for economics for creators (see ‘Rebalancing the Song Economy’ report)
- A Standard Taxonomy for Peer Review <https://osf.io/68rnz/>
- <https://theoryandpractice.citizenscienceassociation.org/articles/10.5334/cstp.294/>
- Humanitarian data from UN <https://3w.unocha.org/>

*This impact assessment has been piloted with the following kinds of research; Chemical Sciences, Medical and Health Sciences, History and Archaeology, and Philosophy and Religious Studies, Environmental Sciences, Agricultural and Veterinary Sciences, Engineering, Education, Studies in Creative Arts and Writing, Language Communication and Culture, and Indigenous research.(120)

267 Table 6: Detailed summary of STARDIT solutions to current limitations in standardised reporting

Limitations of current models and frameworks	Solutions to current limitations proposed by this system
<p>There are numerous models and reporting frameworks, which change according to the research discipline – making it difficult for governments and international organisations to assess impacts from interventions and creating challenges and for global change research(132).</p> <p>The principles of involvement in research and other interventions (and associated methodologies such as participatory action research and citizen science) are the same across all fields (health, environmental, basic, community based participatory, education), yet a significant number of models and frameworks are specific to health research. For example, existing models such as GRIPP2 are only appropriate for certain kinds of health and social care research(394).</p> <p>Recent international consensus statements have clearly defined a role for the public in research which is ‘data intensive’, a kind of research which will continue to grow in importance(23). While such statements call for both an assessment of impact and an evaluation of the process, numerous studies call for the creation of a standardised framework to report involvement in this kind of research(20–22).</p>	<p>This system creates a standardised way for reporting initiatives that is consistent across all disciplines of research.</p> <p>This system does not attempt to replace any other model or system, but to ‘sit above’ them, complimenting and incorporating other systems when required.</p> <p>Journals can adopt the online reporting system and research funders can require completion.</p>
<p>Most other models and frameworks require research authors to know about them and adopt that framework</p>	<p>Those reporting on initiatives are encouraged to adopt the reporting system when submitting papers for publication (by trialling the system with publishers and research funders). The system is intended to create new metrics for research impact, which over time, will create an incentive for researchers to report involvement and impact. While initial motivation for reporting may be intrinsic, as more partner organisations (such as research funders) adopt the</p>

	system, there may be formal requirements to report, or a form of prestige associated with being able to report impacts.
Some models and frameworks are behind paywalls, or remain ‘intellectual property’, are not in the public domain to allow adaptation or continuous improvement or are not publicly accessible.	The model will be licensed under Creative Commons license (Attribution-NonCommercial-NoDerivs CC BY-NC-ND) with the quality of any future iterations being the responsibility of not-for-profit host organisations.
The linguistic variation between terms such as ‘involvement’, ‘engagement’ and ‘participation’ makes objective comparisons of interventions difficult. Concepts do not always easily translate to other languages, despite many research projects being multi-lingual in scope and impact.	The system will use an ‘action-based’ approach to the spectrum of involvement (395) – requiring clearly described ‘tasks’, negating a need for fixed definitions of concepts such as ‘involvement’, ‘engagement’ and ‘participation’. Where possible, terms and concepts will be mapped to a taxonomy which will allow translation between languages. The participatory model of the project means that anyone will be able to get involved in co-designing and co-defining terms use in the system.
Time delays mean that evaluating the impact of research after the project is difficult to achieve and difficult to disseminate (225). A number of reviews have called for standardised ways of reporting involvement in research over extended periods of time in order to improve evidence-informed ways of involving people, and to understand ‘works, for whom, why, and in what circumstances’ (6–8).	The reports are ‘living’ and can be updated over time, allowing impact from research projects to be captured after the project has completed. This aligns with the goals of both the UN and the Organisation for Economic Co-operation and Development (OECD) Development Assistance Committee which attempts to evaluate short, medium and long term impacts from initiatives(49).
	The ‘purpose’ or the ‘why’ of the initiative and the purpose of involving people in certain tasks can also be reported in a consistent way.
	The reports will be hosted by the WikiJournal of Science and quality-control (checking citations) will be carried out by the Editors.

The reports will create an evidence-base for future living systematic reviews to analyse involvement and allow evidence informed involvement.

There is a potential power imbalance and bias in only having certain stakeholders write up research and assess the impacts (for example, only researchers, not research participants or research users).

The reporting system can be led by the authors of the research, and will encourage the inclusion of multiple stakeholders in order to define outcome measures, identify indicators and collect and interpret data (132). It will also provide an opportunity for people involved in the project to be authors of the STARDIT report.

There is often an unhelpful or unnecessary divide between labels like 'researcher', 'participant', 'patient' and 'the public' which are likely to become increasingly blurred – for example, in future citizen science projects and public health genomics (36).

The system treats all with parity, encouraging self-identification to labels which people feel are most appropriate. Anyone can be listed as carrying out any task, regardless of their label.

270 Detailed reporting of design using STARDIT

271 The information below in Table 7 summarises best-practice from a number of international models of co-design and provides practical guidance on how
272 STARDIT can be used at these stages. The column for ‘People’ is a guide to how many people might be involved at each stage, which will depend on the
273 resources of each initiative.

274 Table 7: Detailed reporting of design using STARDIT

Stage	Tasks	People
Stage 1: Idea identified An idea for an intervention, project or research is identified and articulated	1. Articulate the idea in appropriate accessible media, including plain language, simple visuals and other culturally appropriate methods of communication. Report planned initiative	<10
Stage 2: Idea refined The idea is refined with a small group of stakeholders	2. Send out proposed idea and draft involvement plan to all known stakeholders 3. Clarify tasks, expectations, shared values and accountabilities(109–111) 4. Discuss and record who is ‘involving’ who? (112,113) 5. Seek feedback on: a. The context (is the understanding of context accurate? Have the possible and preferred future realities been accurately mapped? Who was involved?)(114) b. The idea (is this a priority? Are others more important or urgent? Who is deciding this?) c. The involvement plan (Can the stakeholders think of better ways to involve people?) d. The language and terms used to describe the idea and the people involved (are people happy to be described as ‘this label’)(6,25)	<20
Stage 3: Stakeholder mapping Existing stakeholders attempt to map who might currently be excluded from the process	6. Ask known stakeholders to agree a map of all those currently involved and all those who are known to be currently absent (25) 7. Explore reasons why people might be excluded and ways of including them (115) Preference Mapping	<20
Stage 4: Co-create communication plan	8. Develop a communication plan to tell people how they can give feedback on the planned idea. This should include clear information about: a. What will be done with this feedback (including who will be involved in analysing it) (25,116) b. How transparent the process will be(109)	<20

Develop a communication plan to invite people to co-create involvement	9. What will be kept confidential to whom and how? Who decides this?	
Stage 5: Share idea and involvement plan Share the idea (according to the communication plan) and ask for feedback on it (including the involvement plan)	10. Using the communication plan (Stage 4), disseminate the idea and the involvement plan, including a clear invitation for people to be involved in the next stages of the process(117).	<100
	Report updated plan Note: the involvement plan could ask for feedback on: <ul style="list-style-type: none"> • What are the potential and preferred outcomes? (114,118) • Who should be involved in the initiative or research? • How those people should be involved in specific tasks, • Which methods and modes of communication should be used. 	
Stage 6: Analyse feedback Collect and analyse feedback, share results.	11. Collect feedback 12. Analyse feedback according to communications plan (Stage 4) (116) 13. Share results of the analysis	>100
Stage 7: Finalise idea and involvement plan Co-create the plan (including the plan for involving people)	14. Informed by the results of the feedback (Stage 6), co-create the plan, including how people will be involved. This should include: <ul style="list-style-type: none"> a. Agreeing budget required for involving people and integrate this into any funding applications (119) b. Agreeing how the idea and the involvement will be evaluated(120) 	>100
	Report final plan	
Stage 8: Evaluate involvement Evaluate the process and the impact of both the initiative and involving people in the initiative	Work in partnership with stakeholders to: <ul style="list-style-type: none"> 15. Appraise the process of involving people (what worked, what could be improved) 16. Evaluate the impact of involving people on the initiative 17. Evaluate the impact of the initiative 	>100

References

1. WHO. One Health. WHO. 2017;
2. World Economic Forum. Annual Report 2018–2019 [Internet]. 2019 [cited 2020 Jan 12]. Available from: <https://www.weforum.org/reports/annual-report-2018-2019>
3. Bertalanffy L von. General system theory : foundations, development, applications. George Braziller; 1969. 295 p.
4. Rosling H, Rosling O, Rönnlund AR. Factfulness. 2018.
5. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. BMJ [Internet]. 2015 Mar 19 [cited 2021 Apr 26];350. Available from: <http://www.bmj.com/>
6. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect [Internet]. 2014 Oct [cited 2016 Apr 1];17(5):637–50. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060910/pdf/HEX-17-637.pdf>
7. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities. Patient [Internet]. 2014 [cited 2017 Mar 17];7(4):387–95. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25034612>
8. Nunn JS, Tiller J, Fransquet PD, Lacaze P. Public Involvement in Global Genomics Research: A Scoping Review. Front Public Heal [Internet]. 2019 Apr 9 [cited 2019 Mar 20];7:79. Available from: <https://www.frontiersin.org/articles/10.3389/fpubh.2019.00079/abstract>
9. Marchal B, van Belle S, van Olmen J, Hoérée T, Kegels G. Is realist evaluation keeping its promise? A review of published empirical studies in the field of health systems research [Internet]. Vol. 18, Evaluation. Sage Publications; 2012 [cited 2021 Apr 15]. p. 192–212. Available from: <https://research.itg.be/en/publications/is-realist-evaluation-keeping-its-promise-a-review-of-published-e>
10. United Nations. Data Strategy of the Secretary-General for Action by Everyone, Everywhere [Internet]. 2020 [cited 2020 Nov 12]. Available from: https://www.un.org/en/content/datastrategy/images/pdf/UN_SG_Data-Strategy.pdf
11. United Nations. Paris Agreement [Internet]. 2015 [cited 2021 Apr 15]. Available from: http://unfccc.int/files/essential_background/convention/application/pdf/english_paris_agreement.pdf
12. Global Biodiversity Information Facility (GBIF). What is GBIF? [Internet]. [cited 2020 May 11]. Available from: <https://www.gbif.org/what-is-gbif>
13. UN Environment Programme World Conservation Monitoring Centre. A review of barriers to the sharing of biodiversity data and information, with recommendations for eliminating them. In 2012 [cited 2021 Apr 15]. Available from: <https://web.archive.org/web/20171010204051/https://www.cbd.int/doc/meetings/cop/cop-11/information/cop-11-inf-08-en.doc>
14. Ganzevoort W, van den Born RJG, Halffman W, Turnhout S. Sharing biodiversity data: citizen scientists' concerns and motivations. Biodivers Conserv [Internet]. 2017 Nov 1 [cited 2021

- 317 Apr 15];26(12):2821–37. Available from: [https://link.springer.com/article/10.1007/s10531-](https://link.springer.com/article/10.1007/s10531-017-1391-z)
318 017-1391-z
- 319 15. Crowe S, Fenton M, Hall M, Cowan K, Chalmers I. Patients', clinicians' and the research
320 communities' priorities for treatment research: there is an important mismatch. *Res Involv*
321 *Engagem* [Internet]. 2015;1(1):2. Available from:
322 <http://www.researchinvolvement.com/content/1/1/2>
- 323 16. Silvertown J. A new dawn for citizen science [Internet]. Vol. 24, *Trends in Ecology and*
324 *Evolution*. Elsevier Ltd; 2009 [cited 2021 May 6]. p. 467–71. Available from:
325 <http://www.cell.com/article/S016953470900175X/fulltext>
- 326 17. Auerbach J, Barthelmess EL, Cavalier D, Cooper CB, Fenck H, Haklay M, et al. The problem
327 with delineating narrow criteria for citizen science [Internet]. Vol. 116, *Proceedings of the*
328 *National Academy of Sciences of the United States of America*. National Academy of Sciences;
329 2019 [cited 2021 May 6]. p. 15336–7. Available from:
330 www.pnas.org/cgi/doi/10.1073/pnas.1909278116
- 331 18. Staley K, Barron D. Learning as an outcome of involvement in research: what are the
332 implications for practice, reporting and evaluation? *Res Involv Engagem* [Internet]. 2019 Mar
333 12 [cited 2020 Apr 30];5(1):14. Available from:
334 <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0147-1>
- 335 19. Dawson S, Ruddock A, Parmar V, Morris R, Cheraghi-Sohi S, Giles S, et al. Patient and public
336 involvement in doctoral research: Reflections and experiences of the PPI contributors and
337 researcher. *Res Involv Engagem* [Internet]. 2020 May 11 [cited 2020 Nov 9];6(1):23. Available
338 from: [https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00201-](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00201-w)
339 w
- 340 20. Dukhanin V, Topazian R, DeCamp M. Metrics and Evaluation Tools for Patient Engagement in
341 Healthcare Organization- and System-Level DecisionMaking: A Systematic Review. *Int J Heal*
342 *Policy Manag*. 2018;
- 343 21. Crocker JC, Ricci-Cabello I, Parker A, Hirst JA, Chant A, Petit-Zeman S, et al. Impact of patient
344 and public involvement on enrolment and retention in clinical trials: systematic review and
345 meta-analysis. *BMJ* [Internet]. 2018 Nov 28 [cited 2019 Jan 10];363:k4738. Available from:
346 <http://www.ncbi.nlm.nih.gov/pubmed/30487232>
- 347 22. Regan de Bere S, Nunn S. Towards a pedagogy for patient and public involvement in medical
348 education. *Med Educ* [Internet]. 2016 Jan [cited 2019 Sep 1];50(1):79–92. Available from:
349 <http://www.ncbi.nlm.nih.gov/pubmed/26695468>
- 350 23. Aitken M, Tully MP, Porteous C, Denegri S, Cunningham-Burley S, Banner N, et al. Consensus
351 Statement on Public Involvement and Engagement with Data-Intensive Health Research.
352 *Under Rev* [Internet]. 2018 Feb 12 [cited 2019 Feb 15];4(1). Available from:
353 <https://ijpds.org/article/view/586>
- 354 24. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for
355 supporting patient and public involvement in research: Systematic review and co-design pilot.
356 *Heal Expect* [Internet]. 2019 Aug 22 [cited 2021 Jan 18];22(4):785–801. Available from:
357 <https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.12888>
- 358 25. Bergold J, Stefan T. Participatory Research Methods : A Methodological Approach in Motion.
359 *Forum Qual Soc Res* [Internet]. 2012 [cited 2017 Jun 19];13(1):Art. 1. Available from:
360 <http://www.qualitative-research.net/index.php/fqs/article/view/1801/3334>

26. Chambers R. The origins and practice of participatory rural appraisal. *World Dev.* 1994;22(7):953–69.
27. Kullenberg C, Kasperowski D. What Is Citizen Science? – A Scientometric Meta-Analysis. Dorta-González P, editor. *PLoS One* [Internet]. 2016 Jan 14 [cited 2021 Apr 28];11(1):e0147152. Available from: <https://dx.plos.org/10.1371/journal.pone.0147152>
28. Eitzel M V, Cappadonna JL, Santos-Lang C, Duerr RE, Virapongse A, West SE, et al. Citizen Science Terminology Matters: Exploring Key Terms. *Citiz Sci Theory Pract* [Internet]. 2017 Jun 5 [cited 2021 Apr 28];2(1):1. Available from: <https://doi.org/10.5334/cstp.96>
29. Vetter J. Introduction: Lay participation in the history of scientific observation [Internet]. Vol. 24, *Science in Context*. Cambridge University Press; 2011 [cited 2021 Apr 28]. p. 127–41. Available from: <https://doi.org/10.1017/S0269889711000032>
30. Deverka PA, Lavalley DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, et al. Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. *J Comp Eff Res* [Internet]. 2012 Mar 5 [cited 2019 Jan 29];1(2):181–94. Available from: <https://www.futuremedicine.com/doi/10.2217/ce.12.7>
31. Burton H, Adams M, Bunton R, Schröder-Bäck P, Schroder-Back P, Schröder-Bäck P, et al. Developing stakeholder involvement for introducing public health genomics into public policy. *Public Health Genomics* [Internet]. 2009 [cited 2017 Aug 2];12(1):11–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19023186>
32. Komesaroff PA, Kerridge I, Lipworth W. Conflicts of interest: new thinking, new processes. *Intern Med J* [Internet]. 2019 May 1 [cited 2021 May 5];49(5):574–7. Available from: <https://onlinelibrary.wiley.com/doi/full/10.1111/imj.14233>
33. Gross M, McGoey L. *Routledge International Handbook of Ignorance Studies* (Routledge International Handbooks) [Internet]. 2015. Available from: <https://www.routledge.com/Routledge-International-Handbook-of-Ignorance-Studies/Gross-McGoey/p/book/9780415718967>
34. Lexchin J, Bero LA, Djulbegovic B, Clark O. Pharmaceutical industry sponsorship and research outcome and quality: systematic review. *BMJ* [Internet]. 2003 May 31 [cited 2015 Dec 19];326(7400):1167–70. Available from: <http://www.bmj.com/content/326/7400/1167?-=>
35. Katz AS, Hardy BJ, Firestone M, Lofters A, Morton-Ninomiya ME. Vagueness, power and public health: use of ‘vulnerable’ in public health literature. *Crit Public Health* [Internet]. 2020 Oct 19 [cited 2021 Apr 15];30(5):601–11. Available from: <https://www.tandfonline.com/doi/abs/10.1080/09581596.2019.1656800>
36. Nunn JS, Scott CL, Stubbs JW, Cherry SF, Bismark MM. *Involving the Public in Rare Cancer Care and Research*. Textbook of Uncommon Cancer. 2017.
37. Nunn J, Crawshaw M, Lacaze P. Co-Designing Genomics Research With A Large Group of Donor-Conceived Siblings [Internet]. 2020 Nov [cited 2020 Dec 17]. Available from: <https://www.researchsquare.com/article/rs-100595/v1>
38. Nunn JS, Gwynne K, Gray S, Lacaze P. Involving people affected by a rare condition in shaping future genomic research. *Res Involv Engagem* [Internet]. 2021 Dec 15 [cited 2021 Mar 16];7(1):14. Available from: <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-021-00256-3>
39. Science For All. Beta - Science For All [Internet]. [cited 2021 Aug 6]. Available from: <https://scienceforall.world/stardit/beta/>

40. Nunn JS, Gwynne K, Gray S, Lacaze P. Involving People Affected by a Rare Condition in Shaping Future Genomic Research. 2020 Aug 20 [cited 2020 Oct 4]; Available from: <https://www.researchsquare.com/article/rs-62242/v1>
41. Nunn JS, Sulovski M, Tiller J, Holloway B, Ayton D, Lacaze P. Involving Elderly Research Participants in the Co-Design of a Future Multi-Generational Cohort Study.
42. Jack S Nunn, Merrin Sulovski, Jane Tiller, Bruce Holloway, Darshini Ayton, Paul Lacaze. Involving Elderly Research Participants in the Co-Design of a Future Multi-Generational Cohort Study [Internet]. 2020 Aug [cited 2020 Aug 11]. Available from: <https://www.researchsquare.com/article/rs-54058/v1>
43. Cheng Y-Y, Nunn J, Skinner J, Rambaldini B, Boughtwood T, Calma T, et al. A Pathway to Precision Medicine for Aboriginal Australians: A Study Protocol. *Methods Protoc* 2021, Vol 4, Page 42 [Internet]. 2021 Jun 21 [cited 2021 Aug 6];4(2):42. Available from: <https://www.mdpi.com/2409-9279/4/2/42/html>
44. Nunn JS. Science for All - Publicly funded research report (June 2018-December 2019) [Internet]. 2019 [cited 2020 May 12]. Available from: <https://doi.org/10.26181/5eba630a64e08>
45. Nunn JS. STARDIT: Wild DNA [Internet]. [cited 2021 Aug 6]. Available from: https://web.archive.org/web/20210805233637/https://wikispore.wmflabs.org/wiki/Special:FormEdit/STARDIT/Wild_DNA
46. Nunn J, Chang S. What are Systematic Reviews? *WikiJournal Med* [Internet]. 2020 Nov 9 [cited 2020 Nov 23];7(1):5. Available from: https://en.wikiversity.org/wiki/WikiJournal_of_Medicine/What_are_Systematic_Reviews%3F
47. Nunn J, Chang S. What are systematic reviews? *WikiJournal Med* [Internet]. 2020 Nov 9 [cited 2021 Apr 21];7(1):1–11. Available from: https://en.wikiversity.org/wiki/WikiJournal_of_Medicine/What_are_Systematic_Reviews%3F
48. STARDIT Report: What is a systematic review? - Wikidata [Internet]. [cited 2021 Apr 21]. Available from: <https://www.wikidata.org/w/index.php?title=Q101116128&oldid=1303112868>
49. United Nations Evaluation Group. Detail of Impact Evaluation Guidance Document [Internet]. 2013 [cited 2020 May 6]. Available from: <https://web.archive.org/web/20190909065035/http://www.uneval.org/document/detail/1433>
50. Marine Stewardship Council. Marine Stewardship Council [Internet]. 2020. Available from: <https://web.archive.org/web/20200421033733/https://www.msc.org/>
51. B Lab. Certified B Corporations [Internet]. 2020. Available from: <https://web.archive.org/web/20200421033526/https://bcorporation.net/>
52. Fanelli D. How Many Scientists Fabricate and Falsify Research? A Systematic Review and Meta-Analysis of Survey Data. Tregenza T, editor. *PLoS One* [Internet]. 2009 May 29 [cited 2021 Apr 21];4(5):e5738. Available from: <https://dx.plos.org/10.1371/journal.pone.0005738>
53. Clark TD. Science, lies and video-taped experiments. *Nature* [Internet]. 2017 Feb 9 [cited 2021 Apr 21];542(7640):139. Available from: <http://www.nature.com/news/science-lies-and-video-taped-experiments-1.21432>
54. Huber B, Barnidge M, Gil de Zúñiga H, Liu J. Fostering public trust in science: The role of social

- media. Public Underst Sci [Internet]. 2019 Oct 1 [cited 2021 Apr 21];28(7):759–77. Available from: <https://pubmed.ncbi.nlm.nih.gov/31524092/>
55. Braun R. The Public's Growing Distrust of Science? Nat Biotechnol [Internet]. 1999 Dec [cited 2021 Apr 21];17(S5):14–14. Available from: <http://biotech.nature.com>
56. UNESCO. Local knowledge, global goals [Internet]. 2017 [cited 2021 Apr 21]. Available from: <https://unesdoc.unesco.org/ark:/48223/pf0000259599>
57. Linklater WL. Science and Management in a Conservation Crisis: a Case Study with Rhinoceros. Conserv Biol [Internet]. 2003 Aug 1 [cited 2021 Apr 21];17(4):968–75. Available from: <http://doi.wiley.com/10.1046/j.1523-1739.2003.01449.x>
58. Plotz RD, Grecian WJ, Kerley GIH, Linklater WL. Standardising Home Range Studies for Improved Management of the Critically Endangered Black Rhinoceros. Roca AL, editor. PLoS One [Internet]. 2016 Mar 30 [cited 2021 Apr 21];11(3):e0150571. Available from: <https://dx.plos.org/10.1371/journal.pone.0150571>
59. Ripple WJ, Wolf C, Newsome TM, Galetti M, Alamgir M, Crist E, et al. World Scientists' Warning to Humanity: A Second Notice. Bioscience [Internet]. 2017 Dec 1 [cited 2021 Apr 21];67(12):1026–8. Available from: <https://academic.oup.com/bioscience/article/67/12/1026/4605229>
60. Nordheim L V., Gundersen MW, Espehaug B, Guttersrud Ø, Flottorp S. Effects of School-Based Educational Interventions for Enhancing Adolescents Abilities in Critical Appraisal of Health Claims: A Systematic Review. Zhou X, editor. PLoS One [Internet]. 2016 Aug 24 [cited 2019 Apr 5];11(8):e0161485. Available from: <http://dx.plos.org/10.1371/journal.pone.0161485>
61. Nsangi A, Semakula D, Oxman AD, Austvoll-Dahlgren A, Oxman M, Rosenbaum S, et al. Effects of the Informed Health Choices primary school intervention on the ability of children in Uganda to assess the reliability of claims about treatment effects: a cluster-randomised controlled trial. Lancet [Internet]. 2017 Jul 22 [cited 2018 Jun 11];390(10092):374–88. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28539194>
62. National Institute for Health Research. Briefing note eight: Ways that people can be involved in the research cycle [Internet]. National Institute for Health Research. 2017 [cited 2017 Jun 5]. Available from: <http://web.archive.org/web/20170605035051/http://www.invo.org.uk/posttypresource/where-and-how-to-involve-in-the-research-cycle/>
63. Health Research Authority. Public Involvement (Health Research Authority) [Internet]. 2019 [cited 2019 Jul 18]. Available from: <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/>
64. Woolley JP, McGowan ML, Teare HJA, Coathup V, Fishman JR, Settersten RA, et al. Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives. BMC Med Ethics [Internet]. 2016 Jun 4 [cited 2021 May 5];17(1):1–17. Available from: <https://bmcmethics.biomedcentral.com/articles/10.1186/s12910-016-0117-1>
65. Sousa S. Social Participation in the Assessment of Health Technologies for Health Systems: findings from a Synthesis of Qualitative Evidence. 2017 [cited 2021 May 5]; Available from: https://aagts.brasilia.fiocruz.br/wp-content/uploads/2020/10/Relatorio_POPART_final.pdf
66. Nickerson RC, Varshney U, Muntermann J. A method for taxonomy development and its application in information systems. Eur J Inf Syst [Internet]. 2013 Jun 19 [cited 2021 Mar

- 7];22(3):336–59. Available from: <https://link.springer.com/article/10.1057/ejis.2012.26>
67. Gruber T. Ontology of folksonomy: A mash-up of apples and oranges. *Int J Semant Web Inf Syst* [Internet]. 2007 Jan 1 [cited 2021 May 3];3(1):1–11. Available from: <https://www.igi-global.com/article/ontology-folksonomy-mash-apples-oranges/2828>
68. Zhang Y, Ogletree A, Greenberg J, Rowell C. Controlled vocabularies for scientific data: Users and desired functionalities. *Proc Assoc Inf Sci Technol* [Internet]. 2015 Jan 24 [cited 2021 Apr 26];52(1):1–8. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1002/pras.2015.145052010054>
69. Cook T, Abma T, Gibbs L, Gangarova T, Harris J, Kleba ME, et al. Position Paper No. 3: Impact in Participatory Health Research [Internet]. 2020 [cited 2020 May 24]. Available from: http://www.icphr.org/uploads/2/0/3/9/20399575/icphr_position_paper_3_impact_-_march_2020__1_.pdf
70. International Collaboration for Participatory Health Research (ICPHR). Position Paper 1: What is Participatory Health Research? Version: May 2013 [Internet]. International Collaboration for Participatory Health Research. 2013 [cited 2017 Jun 13]. 1–33 p. Available from: http://www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_definition_-_version_may_2013.pdf
71. Kemmis S, Nixon R, McTaggart R. The Action Research Planner: Doing Critical Participatory Action Research. [Internet]. Springer eBooks. 2014 [cited 2018 Apr 5]. Available from: https://books.google.com.au/books?id=GB3IBAAQBAJ&vq=collective+self+reflection&source=gbs_navlinks_s
72. Baum F, Macdougall C, Smith D. Participatory action research. *J Epidemiol Community Heal* [Internet]. 2006 Oct [cited 2017 Jun 19];60(60):854–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16973531>
73. United Nations. Universal Declaration of Human Rights [Internet]. 1948. Available from: http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf
74. Report of the Secretary-General, Nations U, Assembly UNG. Strengthening the role of the United Nations in enhancing the effectiveness of the principle of periodic and genuine elections and the promotion of democratization [Internet]. 2013 [cited 2019 Apr 17]. Available from: <https://digitallibrary.un.org/record/827187>
75. UN Environment Programme. Why does environmental rights and governance matter? [Internet]. 2021 [cited 2021 Feb 5]. Available from: <https://www.unenvironment.org/explore-topics/environmental-governance/why-does-environmental-governance-matter>
76. United Nations For Indigenous Peoples. Indigenous Peoples at the UN [Internet]. 2018 [cited 2019 Apr 16]. Available from: <https://www.un.org/development/desa/indigenouspeoples/about-us.html>
77. Nunn JS, Sulovski M, Tiller J, Holloway B, Ayton D, Lacaze P. Involving elderly research participants in the co-design of a future multi-generational cohort study. *Res Involv Engagem* [Internet]. 2021 Dec 3 [cited 2021 May 5];7(1):23. Available from: <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-021-00271-4>
78. Bromley DW. The commons, common property, and environmental policy. *Environ Resour Econ* [Internet]. 1992 Jan [cited 2019 Apr 17];2(1):1–17. Available from: <http://link.springer.com/10.1007/BF00324686>
79. Butler JRA, Tawake A, Skewes T, Tawake L, McGrath V. Integrating traditional ecological

- knowledge and fisheries management in the torres strait, Australia: The catalytic role of turtles and dugong as cultural keystone species. *Ecol Soc* [Internet]. 2012 Dec 10 [cited 2021 Apr 26];17(4). Available from: <http://dx.doi.org/10.5751/>
80. Rachel Feltman. Orangutan granted rights of personhood in Argentina. *The Washington Post* [Internet]. 2014 [cited 2019 Apr 17]; Available from: https://www.washingtonpost.com/news/speaking-of-science/wp/2014/12/22/orangutan-granted-rights-of-personhood-in-argentina/?noredirect=on&utm_term=.53d1313c54bc
 81. Hutchison A. The Whanganui River as a Legal Person. *Altern Law J* [Internet]. 2014 Sep 1 [cited 2019 Apr 17];39(3):179–82. Available from: <http://journals.sagepub.com/doi/10.1177/1037969X1403900309>
 82. O'Donnell E. Legal Rights for Rivers: Competition, Collaboration and Water Governance [Internet]. 2018 [cited 2021 Apr 26]. 202 p. Available from: <https://www.routledge.com/Legal-Rights-for-Rivers-Competition-Collaboration-and-Water-Governance/ODonnell/p/book/9780367584160>
 83. Genome British Columbia. Genomics Positively Affects Life, Every Day [Internet]. 2019 [cited 2019 Jul 18]. Available from: https://www.genomebc.ca/wp-content/uploads/2019/06/GBC-4228-2018-AR-FINAL_WEB.pdf?utm_source=Master+List&utm_campaign=8c36d44d96-ANNUAL_RPT_CAMPAIGN_2019_07_10&utm_medium=email&utm_term=0_007b42effb-8c36d44d96-96302171&mc_cid=8c36d44d96&mc_eid=40205f8c68
 84. Indigenous Corporate Training. Who owns Traditional Ecological Knowledge? [Internet]. 2013 [cited 2019 Jul 18]. Available from: <https://www.ictinc.ca/blog/owns-tek>
 85. Rubis JM. The orang utan is not an indigenous name: knowing and naming the maias as a decolonizing epistemology. *Cult Stud* [Internet]. 2020 Sep 2 [cited 2021 Apr 26];34(5):811–30. Available from: <https://www.tandfonline.com/doi/abs/10.1080/09502386.2020.1780281>
 86. Rubis JM, Theriault N. Concealing protocols: conservation, Indigenous survivance, and the dilemmas of visibility. *Soc Cult Geogr* [Internet]. 2020 Sep 1 [cited 2021 Apr 26];21(7):962–84. Available from: <https://www.tandfonline.com/doi/abs/10.1080/14649365.2019.1574882>
 87. Moher D, Schulz KF, Simera I, Altman DG. Guidance for Developers of Health Research Reporting Guidelines. *PLoS Med* [Internet]. 2010 Feb 16 [cited 2019 Jun 12];7(2):e1000217. Available from: <http://dx.plos.org/10.1371/journal.pmed.1000217>
 88. INVOLVE. Guidance on co-producing a research project [Internet]. 2018 [cited 2018 Mar 14]. Available from: https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
 89. Macaulay AC. Participatory research: What is the history? Has the purpose changed? *Fam Pract* [Internet]. 2016 Dec 18 [cited 2017 Jun 20];35(3):cmw117. Available from: <https://academic.oup.com/fampra/article-lookup/doi/10.1093/fampra/cmw117>
 90. Jack S Nunn. WikiJournal Youth Salon Evaluation Report: Future Knowledge [Internet]. Melbourne, Australia; 2019 [cited 2020 Sep 3]. Available from: https://upload.wikimedia.org/wikipedia/commons/d/de/WikiJournal_Youth_Salon_Evaluation_Report_-_Science_for_All.pdf
 91. Science for All. About - Science For All [Internet]. [cited 2021 Apr 26]. Available from: <https://web.archive.org/web/20210426041650/https://scienceforall.world/about/>
 92. The EQUATOR Network. Developing your reporting guideline [Internet]. 2018 [cited 2020 May 7]. Available from: <https://www.equator-network.org/toolkits/developing-a-reporting->

guideline/developing-your-reporting-guideline/

93. Wang X, Chen Y, Yang N, Deng W, Wang Q, Li N, et al. Methodology and reporting quality of reporting guidelines: systematic review. BMC Med Res Methodol [Internet]. 2015 Dec 22 [cited 2020 Sep 22];15(1):74. Available from: <http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-015-0069-z>
94. Banno M, Tsujimoto Y, Kataoka Y. The majority of reporting guidelines are not developed with the Delphi method: a systematic review of reporting guidelines. J Clin Epidemiol [Internet]. 2020 Aug 1 [cited 2020 Sep 22];124:50–7. Available from: <http://www.jclinepi.com/article/S0895435619310996/fulltext>
95. Science For All. STARDIT [Internet]. [cited 2021 Jan 17]. Available from: <https://scienceforall.world/stardit/>
96. Jack Nunn. STARDIT Public Consultation Report – September To December 2019 [Internet]. 2020 [cited 2020 Apr 30]. Available from: <https://doi.org/10.26181/5e8c0dd2976b8>
97. Nunn JS. Standardised Data on Initiatives (STARDIT) Public consultation report – September 2019 to May 2021 [Internet]. 2021. Available from: <https://doi.org/10.26181/611dfcf12c6a9>
98. Kharas H. Trends And Issues In Development Aid [Internet]. 2007 [cited 2021 Apr 15]. Available from: https://www.brookings.edu/wp-content/uploads/2016/06/11_development_aid_kharas.pdf
99. Turki H, Shafee T, Hadj Taieb MA, Ben Aouicha M, Vrandečić D, Das D, et al. Wikidata: A large-scale collaborative ontological medical database. Vol. 99, Journal of Biomedical Informatics. Academic Press Inc.; 2019. p. 103292.
100. Sainsbury Institute. What is a Japanese Living National Treasure? [Internet]. 2020 [cited 2020 Sep 8]. Available from: <https://web.archive.org/web/20200908051559/https://www.sainsbury-institute.org/info/what-is-a-japanese-living-national-treasure>
101. Chambers LE, Plotz RD, Dossis T, Hiriasia DH, Malsale P, Martin DJ, et al. A database for traditional knowledge of weather and climate in the Pacific. Meteorol Appl. 2017;24(3).
102. Malsale P, Sanau N, Tofaeono TI, Kavisi Z, Willy A, Mitiepo R, et al. Protocols and Partnerships for Engaging Pacific Island Communities in the Collection and Use of Traditional Climate Knowledge. Bull Am Meteorol Soc [Internet]. 2018 Dec 7 [cited 2019 Mar 21];99(12):2471–89. Available from: <http://journals.ametsoc.org/doi/10.1175/BAMS-D-17-0163.1>
103. Lane R, McNaught R. Building gendered approaches to adaptation in the Pacific. Gend Dev [Internet]. 2009 [cited 2021 Apr 26];17(1):67–80. Available from: <https://www.tandfonline.com/doi/abs/10.1080/13552070802696920>
104. Balakrishnan R. Rural women and food security in Asia and the Pacific: Prospects and paradoxes. Rap Publication. 2005. 30 p.
105. UNESCO. Convention for the Protection of Cultural Property in the Event of Armed Conflict with Regulations for the Execution of the Convention [Internet]. 1999 [cited 2021 May 3]. Available from: http://portal.unesco.org/en/ev.php-URL_ID=13637&URL_DO=DO_TOPIC&URL_SECTION=201.html
106. Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare [Internet]. Vol. 23, BMJ Quality and Safety. BMJ Publishing Group; 2014 [cited 2021 May 3]. p. 290–8.

- Available from: <http://dx.doi.org/10.1136/bmjqs->
107. World Health Organisation. Declaration of Alma-Ata [Internet]. Alma-Ata; 1978 [cited 2018 Jun 25]. Available from: http://www.who.int/publications/almaata_declaration_en.pdf?ua=1
 108. Oliver JL, Brereton M, Watson DM, Roe P. Listening to save wildlife: Lessons learnt from use of acoustic technology by a species recovery team. In: DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference [Internet]. New York, NY, USA: Association for Computing Machinery, Inc; 2019 [cited 2021 May 3]. p. 1335–48. Available from: <https://dl.acm.org/doi/10.1145/3322276.3322360>
 109. Patient Focused Medicines Development. Patient Engagement Quality Guidance Tool [Internet]. 2018 [cited 2019 Mar 13]. Available from: <https://patientfocusedmedicine.org/peqg/patient-engagement-quality-guidance-scenario-1.pdf>
 110. Collins M. PiiAF The Public Involvement Impact Assessment Framework Guidance [Internet]. 2014 [cited 2017 Oct 4]. p. 1–8. Available from: <http://piiاف.org.uk/documents/piiaf-guidance-jan14.pdf>
 111. WHO. Supporting the Use of Research Evidence (SURE) [Internet]. WHO. World Health Organization; 2013 [cited 2019 Apr 5]. Available from: <https://www.who.int/evidence/sure/en/>
 112. Stickley T, Basset T. Learning about Mental Health Practice [Internet]. Learning about Mental Health Practice. Wiley; 2008 [cited 2017 Aug 30]. 614 p. Available from: https://books.google.com.au/books?id=E8epVc6d5bYC&dq='Service+User+Involvement'+in+Learning+About+Mental+Health+Practice&source=gbs_navlinks_s
 113. Alison Faulkner. National Involvement Standards Involvement for influence [Internet]. 2015 [cited 2017 Aug 30]. Available from: <http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf>
 114. Hancock T, Bezold C. Possible Futures, Preferebale Futures. Healthcare Forum Journal. 1994. p. 23–9.
 115. INVOLVE. National Standards for Public Involvement [Internet]. 2018 [cited 2019 Jan 29]. Available from: <http://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/>
 116. Gretta Pecl, Chris Gillies, Carla Sbrocchi, Philip Roetman. Building Australia Through Citizen Science [Internet]. 2015 [cited 2017 Aug 24]. Available from: http://www.chiefscientist.gov.au/wp-content/uploads/Citizen-science-OP_web.pdf
 117. Brett J, Staniszewska S, Mockford C, Seers K, Herron-marx S, Bayliss H. The PIRICOM Study : A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. 2010 [cited 2017 Mar 27];1–292. Available from: <http://www.ukcrc.org/wp-content/uploads/2014/03/Piricom+Review+Final+2010.pdf>
 118. BehaviourWorks Australia. The BehaviourWorks Method [Internet]. 2019 [cited 2020 Apr 30]. Available from: <https://www.behaviourworksaustralia.org/the-method/>
 119. European Patients' forum. The Value + Toolkit [Internet]. 2013 [cited 2016 Aug 22]. Available from: https://webgate.ec.europa.eu/chafea_pdb/assets/files/pdb/2007117/2007117_value_toolkit

- 667 .pdf
- 668 120. Australian Research Council. Engagement and Impact Assessment Pilot Report [Internet].
669 2018 [cited 2019 Feb 5]. Available from: [https://www.arc.gov.au/engagement-and-impact-](https://www.arc.gov.au/engagement-and-impact-assessment/ei-pilot-overview)
670 [assessment/ei-pilot-overview](https://www.arc.gov.au/engagement-and-impact-assessment/ei-pilot-overview)
- 671 121. INVOLVE. Co-production in Action: Number One [Internet]. Southampton; 2019 [cited 2019
672 Jul 16]. Available from: [https://www.invo.org.uk/wp-](https://www.invo.org.uk/wp-content/uploads/2019/07/Copro_In_Action_2019.pdf)
673 [content/uploads/2019/07/Copro_In_Action_2019.pdf](https://www.invo.org.uk/wp-content/uploads/2019/07/Copro_In_Action_2019.pdf)
- 674 122. ORCID. ORCID [Internet]. 2020 [cited 2020 May 17]. Available from: <https://orcid.org/>
- 675 123. The World Wide Web Consortium (W3C). RDF - Semantic Web Standards [Internet]. [cited
676 2021 Jan 18]. Available from: <https://www.w3.org/RDF/>
- 677 124. Wikimedia Foundation. Wikidata [Internet]. 2020 [cited 2020 May 17]. Available from:
678 https://www.wikidata.org/wiki/Wikidata:Main_Page
- 679 125. Internet Archive. Internet Archive: About IA [Internet]. 2018 [cited 2018 Feb 2]. Available
680 from: <https://archive.org/about/>
- 681 126. Staniszewska S, Denegri S, Matthews R, Minogue V. Reviewing progress in public involvement
682 in NIHR research: developing and implementing a new vision for the future. *BMJ Open*
683 [Internet]. 2018 Jul 1 [cited 2019 Jul 8];8(7):e017124. Available from:
684 <http://www.ncbi.nlm.nih.gov/pubmed/30061427>
- 685 127. Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, et al. The FAIR
686 Guiding Principles for scientific data management and stewardship. *Sci Data* [Internet]. 2016
687 Mar 15 [cited 2019 Apr 25];3:160018. Available from:
688 <http://www.nature.com/articles/sdata201618>
- 689 128. Carroll SR, Garba I, Figueroa-Rodríguez OL, Holbrook J, Lovett R, Materechera S, et al. The
690 CARE Principles for Indigenous Data Governance. *Data Sci J* [Internet]. 2020 Nov 4 [cited 2021
691 Feb 2];19(1):1–12. Available from: [http://datascience.codata.org/articles/10.5334/dsj-2020-](http://datascience.codata.org/articles/10.5334/dsj-2020-043/)
692 [043/](http://datascience.codata.org/articles/10.5334/dsj-2020-043/)
- 693 129. Turki H, Taieb MAH, Shafee T, Lubiana T, Jemielniak D, Aouicha M Ben, et al. Representing
694 COVID-19 information in collaborative knowledge graphs: a study of Wikidata. 2020 Sep 14
695 [cited 2021 Feb 5]; Available from: <https://zenodo.org/record/4028483>
- 696 130. Waagmeester A, Stupp G, Burgstaller-Muehlbacher S, Good BM, Griffith M, Griffith OL, et al.
697 Wikidata as a knowledge graph for the life sciences. *Elife*. 2020 Mar 1;9.
- 698 131. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred Reporting Items for Systematic Reviews
699 and Meta-Analyses: The PRISMA Statement. *PLoS Med* [Internet]. 2009 Jul 21 [cited 2019 Jan
700 29];6(7):e1000097. Available from: <https://dx.plos.org/10.1371/journal.pmed.1000097>
- 701 132. Fazey I, Bunse L, Msika J, Pinke M, Preedy K, Evely AC, et al. Evaluating knowledge exchange
702 in interdisciplinary and multi-stakeholder research. *Glob Environ Chang* [Internet]. 2014 Mar
703 1 [cited 2019 Feb 5];25:204–20. Available from:
704 <https://www.sciencedirect.com/science/article/abs/pii/S0959378014000028>
- 705 133. Gradingier F, Britten N, Wyatt K, Froggatt K, Gibson A, Jacoby A, et al. Values associated with
706 public involvement in health and social care research: a narrative review. *Health Expect*
707 [Internet]. 2015 Oct [cited 2017 Apr 10];18(5):661–75. Available from:
708 <http://doi.wiley.com/10.1111/hex.12158>

- 709 134. INVOLVE. Public involvement in research : values and principles framework. 2015 [cited 2018
710 Mar 14];(October). Available from: [http://www.invo.org.uk/wp-](http://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf)
711 [content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf](http://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf)
- 712 135. Biggio B, Roli F. Wild patterns: Ten years after the rise of adversarial machine learning.
713 *Pattern Recognit.* 2018 Dec 1;84:317–31.
- 714 136. Science For All. STARDIT - Science For All [Internet]. 2020 [cited 2020 May 17]. Available from:
715 <https://scienceforall.world/stardit/>
- 716 137. Nunn J, Shafee T, Chang S, Stephens R, Elliott J, Oliver S, et al. Standardised Data on Initiatives
717 - STARDIT: Alpha Version. 2019;
- 718 138. Science for All. Science For All - About [Internet]. 2019 [cited 2019 Jul 8]. Available from:
719 <https://web.archive.org/web/20190708071126/https://scienceforall.world/about/>
- 720 139. Committee on Publication Ethics (COPE). Guidelines on Good Publication Practice. 1997.
- 721 140. Jasanoff S. States of knowledge : the co-production of science and social order [Internet].
722 2004 [cited 2021 May 5]. Available from: [https://www.worldcat.org/title/states-of-](https://www.worldcat.org/title/states-of-knowledge-the-co-production-of-science-and-social-order/oclc/56545415)
723 [knowledge-the-co-production-of-science-and-social-order/oclc/56545415](https://www.worldcat.org/title/states-of-knowledge-the-co-production-of-science-and-social-order/oclc/56545415)
- 724 141. Gagnon Thompson SC, Barton MA. Ecocentric and anthropocentric attitudes toward the
725 environment. *J Environ Psychol.* 1994;14(2):149–57.
- 726 142. Wikimedia Foundation. Phase I Clinical Trial - Wikidata Definition [Internet]. 2019 [cited 2019
727 Jul 4]. Available from: <https://www.wikidata.org/wiki/Q42824069>
- 728 143. National Library of Medicine. Medical Subject Headings. [cited 2019 Jun 12]; Available from:
729 <https://www.nlm.nih.gov/mesh/meshhome.html>
- 730 144. Cochrane. Cochrane crowd [Internet]. 2019 [cited 2019 Sep 12]. Available from:
731 <http://crowd.cochrane.org/index.html>
- 732 145. Uher R. Genomics and the classification of mental illness: Focus on broader categories.
733 *Genome Med.* 2013;
- 734 146. Wikipedia. Google Knowledge Graph [Internet]. [cited 2021 Feb 5]. Available from:
735 https://en.wikipedia.org/w/index.php?title=Google_Knowledge_Graph&oldid=1002573625
- 736 147. Guest G, MacQueen K, Namey E. Applied Thematic Analysis [Internet]. 2455 Teller
737 Road, Thousand Oaks California 91320 United States : SAGE Publications, Inc.; 2012 [cited
738 2019 Feb 18]. Available from: <http://methods.sagepub.com/book/applied-thematic-analysis>
- 739 148. Saldaña J. The Coding Manual for Qualitative Researchers (2nd Ed.) [Internet]. SAGE
740 Publications Inc. SAGE Publications; 2013 [cited 2019 Feb 18]. 1–329 p. Available from:
741 [https://www.cambridge.org/core/product/identifier/CBO9781107415324A009/type/book_p](https://www.cambridge.org/core/product/identifier/CBO9781107415324A009/type/book_part)
742 [art](https://www.cambridge.org/core/product/identifier/CBO9781107415324A009/type/book_part)
- 743 149. Rison RA, Kidd MR, Koch CA. The CARE (CAse REport) guidelines and the standardization of
744 case reports. *J Med Case Rep [Internet].* 2013 Dec 27 [cited 2019 Feb 17];7(1):261. Available
745 from: <http://www.ncbi.nlm.nih.gov/pubmed/24283496>
- 746 150. Elliott JH, Synnot A, Turner T, Simmonds M, Akl EA, McDonald S, et al. Living systematic
747 review: 1. Introduction-the why, what, when, and how. *J Clin Epidemiol [Internet].* 2017 Nov
748 1 [cited 2018 Feb 21];91:23–30. Available from:
749 <http://www.ncbi.nlm.nih.gov/pubmed/28912002>

151. STARDIT + GBIF - Science For All [Internet]. [cited 2021 Aug 19]. Available from:
<https://web.archive.org/web/20210819071238/https://scienceforall.world/stardit/gbif/>
152. iNaturalist. What is the data quality assessment and how do observations qualify to become
"Research Grade" [Internet]. 2020 [cited 2020 Dec 6]. Available from:
<https://www.inaturalist.org/pages/help#quality>
153. Mann J. Health and human rights: if not now, when? *Am J Public Health* [Internet]. 1997 Nov
[cited 2018 Jan 27];96(11):1940–3. Available from:
<http://www.ncbi.nlm.nih.gov/pubmed/17062844>
154. Evans D, Coad J, Cottrell K, Dalrymple J, Davies R, Donald C, et al. Public involvement in
research: assessing impact through a realist evaluation. *Heal Serv Deliv Res* [Internet].
2014;7(3):1–128. Available from:
<http://eprints.uwe.ac.uk/5470/%5Cnhttp://www.heacademy.ac.uk/ijme%5Cnhttp://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-36>
155. Oliver SR, Rees RW, Clarke-Jones L, Milne R, Oakley AR, Gabbay J, et al. A multidimensional
conceptual framework for analysing public involvement in health services research. *Heal
Expect* [Internet]. 2008 Mar [cited 2015 Sep 21];11(1):72–84. Available from:
<http://doi.wiley.com/10.1111/j.1369-7625.2007.00476.x>
156. Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite J. Key concepts in consumer and
community engagement: a scoping meta-review. *BMC Health Serv Res* [Internet]. 2014 Jan 13
[cited 2016 Apr 11];14(1):250. Available from:
<http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-250>
157. Stokes F, Press A, Oliver SR, Liabo K, Stewart R, Rees R. Public involvement in research:
making sense of the diversity. *J Health Serv Res Policy* [Internet]. 2014 [cited 2018 Jan
30];20(1):45–51. Available from:
<http://journals.sagepub.com/doi/pdf/10.1177/1355819614551848>
158. Draper AK, Hewitt G, Rifkin S. Chasing the dragon: Developing indicators for the assessment
of community participation in health programmes. *Soc Sci Med*. 2010 Sep 1;71(6):1102–9.
159. Concannon TW, Grant S, Welch V, Petkovic J, Selby J, Crowe S, et al. Practical Guidance for
Involving Stakeholders in Health Research. *J Gen Intern Med* [Internet]. 2018 Dec 18 [cited
2019 Jan 10];1–6. Available from: <http://link.springer.com/10.1007/s11606-018-4738-6>
160. Collins HM, Evans R. Studies of Expertise and Experience. [cited 2018 Mar 15]; Available from:
<http://journals.sagepub.com/doi/pdf/10.1177/0306312702032002003>
161. Hill S. Involving the Consumer in Health Research. In: Saks M, Allsop J, editors. *Researching
Health: Qualitative, Quantitative and Mixed Methods*. Sage; 2011.
162. Watts A. Alan Watts [Internet]. Wikiquote. [cited 2020 Sep 13]. Available from:
https://web.archive.org/web/20200913043749/https://en.wikiquote.org/wiki/Alan_Watts
163. Manheim D, Garrabrant S. Categorizing Variants of Goodhart's Law. 2018 Mar 12 [cited 2020
Sep 13]; Available from: <http://arxiv.org/abs/1803.04585>
164. Strathern M. 'Improving ratings': audit in the British University system. *Eur Rev* [Internet].
1997 Jul [cited 2020 Sep 13];5(3):305–21. Available from: [/core/journals/european-review/article/improving-ratings-audit-in-the-british-university-system/FC2EE640C0C44E3DB87C29FB666E9AAB](http://core/journals/european-review/article/improving-ratings-audit-in-the-british-university-system/FC2EE640C0C44E3DB87C29FB666E9AAB)
165. Shortell SM, Sehgal NJ, Bibi S, Ramsay PP, Neuhauser L, Colla CH, et al. An Early Assessment

- 793 of Accountable Care Organizations' Efforts to Engage Patients and Their Families. *Med Care*
794 *Res Rev* [Internet]. 2015 Oct 2 [cited 2020 May 6];72(5):580–604. Available from:
795 <http://journals.sagepub.com/doi/10.1177/1077558715588874>
- 796 166. International Civil Aviation Organization. Aircraft Accident and Incident Investigation
797 [Internet]. [cited 2021 Jan 18]. Available from:
798 <https://www.icao.int/safety/airnavigation/aig/pages/documents.aspx>
- 799 167. Victorian Agency for Health Information. About the Victorian Agency for Health Information
800 [Internet]. 2020 [cited 2020 Aug 24]. Available from: <https://vahi.vic.gov.au/about-vahi>
- 801 168. Dillon EC, Tuzzio L, Madrid S, Olden H, Greenlee RT. Measuring the Impact of Patient-Engaged
802 Research: How a Methods Workshop Identified Critical Outcomes of Research Engagement. *J*
803 *Patient-Centered Res Rev*. 2017 Nov 6;4(4):237–46.
- 804 169. Maccarthy J, Guerin S, Wilson AG, Dorris ER. Facilitating public and patient involvement in
805 basic and preclinical health research. Salsberg J, editor. *PLoS One* [Internet]. 2019 May 14
806 [cited 2019 May 27];14(5):e0216600. Available from:
807 <http://dx.plos.org/10.1371/journal.pone.0216600>
- 808 170. Taxonomic Databases Working group (TDWG). Access to Biological Collection Data. 2020
809 [cited 2020 May 11]; Available from: <https://abcd.tdwg.org/>
- 810 171. Taxonomic Databases Working group (TDWG). Biodiversity Information Standards [Internet].
811 [cited 2020 May 11]. Available from: <https://www.tdwg.org/>
- 812 172. Darwin Core Task Group BIS (TDWG). Darwin Core [Internet]. 2020 [cited 2020 May 11].
813 Available from: <https://www.tdwg.org/standards/dwc/>
- 814 173. National Center for Ecological Analysis and Synthesis. Ecological Metadata Language (EML)
815 [Internet]. 2020 [cited 2020 May 11]. Available from: <https://eml.ecoinformatics.org/>
- 816 174. Taxonomic Databases Working group (TDWG). World Geographical Scheme for Recording
817 Plant Distributions [Internet]. [cited 2020 May 11]. Available from:
818 <https://www.tdwg.org/standards/wgsrpd/>
- 819 175. Selinske MJ, Howard N, Fitzsimons JA, Hardy MJ, Smillie K, Forbes J, et al. Monitoring and
820 evaluating the social and psychological dimensions that contribute to privately protected
821 area program effectiveness. *Biol Conserv*. 2019 Jan 1;229:170–8.
- 822 176. Whitburn J, Linklater W, Abrahamse W. Meta-analysis of human connection to nature and
823 proenvironmental behavior. *Conserv Biol* [Internet]. 2020 Feb 12 [cited 2020 Apr
824 30];34(1):180–93. Available from:
825 <https://onlinelibrary.wiley.com/doi/abs/10.1111/cobi.13381>
- 826 177. The Company of Biologists. Author contributions: CRediT taxonomy [Internet]. 2019. [cited
827 2019 Jan 29]. Available from: <http://dev.biologists.org/content/author-contributions>
- 828 178. United States National Library of Medicine. Medical Subject Headings (MeSH) [Internet]. 2020
829 [cited 2020 Oct 1]. Available from: <https://www.nlm.nih.gov/mesh/meshhome.html>
- 830 179. Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, et al.
831 Patient and service user engagement in research: A systematic review and synthesized
832 framework. *Heal Expect* [Internet]. 2015 Oct 1 [cited 2017 Feb 16];18(5):1151–66. Available
833 from: <http://doi.wiley.com/10.1111/hex.12090>
- 834 180. Mark2Cure. About Mark2Cure [Internet]. 2020 [cited 2020 May 10]. Available from:

- 835 <https://mark2cure.org/about/>
- 836 181. Communities For Impact. Virtual Communities For Impact [Internet]. 2019. [cited 2020 Apr
837 29]. Available from: <https://communitiesforimpact.org/>
- 838 182. B Lab. B Impact Assessment [Internet]. 2020 [cited 2020 Apr 27]. Available from:
839 <https://bimpactassessment.net/how-it-works/assess-your-impact>
- 840 183. Deverka PA, Lavalley DC, Desai PJ, Esmail LC, Ramsey SD, Veenstra DL, et al. Stakeholder
841 participation in comparative effectiveness research: defining a framework for effective
842 engagement. J Comp Eff Res [Internet]. 2012 Mar [cited 2019 Jan 29];1(2):181–94. Available
843 from: <http://www.ncbi.nlm.nih.gov/pubmed/22707880>
- 844 184. Australian Government. Climate Active [Internet]. 2021. Available from:
845 <https://www.climateactive.org.au/be-climate-active/certification>
- 846 185. Charity Evaluation Working Group. Defining “evidence” and it’s role in decision making
847 [Internet]. 2020 [cited 2020 May 13]. Available from:
848 <https://www.chewgroup.org.uk/post/defining-evidence-and-it-s-role-in-decision-making>
- 849 186. Evaluation Support Scotland. Evaluation Support Scotland [Internet]. 2020 [cited 2020 May
850 13]. Available from: <http://www.evaluationsupportscotland.org.uk/>
- 851 187. Fundraising Regulator. Code of Fundraising Practice [Internet]. [cited 2021 Jan 11]. Available
852 from: <https://www.fundraisingregulator.org.uk/code>
- 853 188. Australian Charities and Not-for-profits Commission. The Annual Information Statement
854 [Internet]. [cited 2021 Jan 18]. Available from: [https://www.acnc.gov.au/for-charities/annual-](https://www.acnc.gov.au/for-charities/annual-information-statement)
855 [information-statement](https://www.acnc.gov.au/for-charities/annual-information-statement)
- 856 189. Charity Navigator. Charity Navigator [Internet]. Available from:
857 <https://www.charitynavigator.org/index.cfm?bay=content.view&cpid=5593>
- 858 190. Australian Citizen Science Association. 10 Principles of Citizen Science [Internet]. [cited 2021
859 Jan 18]. Available from: <https://citizenscience.org.au/10-principles-of-citizen-science/>
- 860 191. Project Finder | Australian Citizen Science Project Finder [Internet]. [cited 2021 Jan 18].
861 Available from:
862 [https://biocollect.ala.org.au/acsa#isCitizenScience%3Dtrue%26isWorldWide%3Dfalse%26ma](https://biocollect.ala.org.au/acsa#isCitizenScience%3Dtrue%26isWorldWide%3Dfalse%26max%3D20%26sort%3DdateCreatedSort)
863 [x%3D20%26sort%3DdateCreatedSort](https://biocollect.ala.org.au/acsa#isCitizenScience%3Dtrue%26isWorldWide%3Dfalse%26max%3D20%26sort%3DdateCreatedSort)
- 864 192. Citizen Science COST Action. On citizen-science ontology, standards and data [Internet]. 2019
865 [cited 2020 Apr 27]. Available from: [https://cs-](https://cs-eu.net/sites/default/files/media/2019/10/CA15212_WG5_Enschede_minutes.pdf)
866 [eu.net/sites/default/files/media/2019/10/CA15212_WG5_Enschede_minutes.pdf](https://cs-eu.net/sites/default/files/media/2019/10/CA15212_WG5_Enschede_minutes.pdf)
- 867 193. European Union. EU-Citizen.Science [Internet]. 2020 [cited 2020 Apr 27]. Available from:
868 <https://eu-citizen.science/about/>
- 869 194. Göbel C. Open Participatory Research - Four Questions to reflect on Openness in Citizen
870 Science practice. 2019; Available from: <https://osf.io/7etks/>
- 871 195. Göbel C, Nold C, Berditchevskaia A, Haklay M. How Does Citizen Science “Do” Governance?
872 Reflections from the DITOs Project. Citiz Sci Theory Pract. 2019;
- 873 196. SciStarter. SciStarter [Internet]. 2020 [cited 2020 May 6]. Available from:
874 <https://scistarter.org/about>
- 875 197. Soleri D, Long JW, Ramirez-Andreotta MD, Eitemiller R, Pandya R. Finding Pathways to More

- 876 Equitable and Meaningful Public-Scientist Partnerships. *Citiz Sci Theory Pract*. 2016;
- 877 198. Strasser BJ, Baudry J, Mahr D, Sanchez G, Tancoigne E. "Citizen science"? Rethinking science
878 and public participation. *Sci Technol Stud*. 2019;
- 879 199. European Citizen Science Association (ECSA). Ten Principles of Citizen Science [Internet]. 2015
880 [cited 2020 May 6]. Available from: [https://ecsa.citizen-](https://ecsa.citizen-science.net/sites/default/files/ecsa_ten_principles_of_citizen_science.pdf)
881 [science.net/sites/default/files/ecsa_ten_principles_of_citizen_science.pdf](https://ecsa.citizen-science.net/sites/default/files/ecsa_ten_principles_of_citizen_science.pdf)
- 882 200. Citscibio. citscibio - About Us [Internet]. 2020 [cited 2020 May 10]. Available from:
883 <https://citscibio.org/about>
- 884 201. Borda A, Gray K, Fu Y. Research data management in health and biomedical citizen science:
885 practices and prospects. *JAMIA Open*.
- 886 202. QuestaGame. Core Values [Internet]. 2020 [cited 2020 Oct 2]. Available from:
887 <https://questagame.com/core-values>
- 888 203. Sacristán JA, Aguarón A, Avendaño-Solá C, Garrido P, Carrión J, Gutiérrez A, et al. Patient
889 involvement in clinical research: Why, when, and how. Vol. 10, *Patient Preference and*
890 *Adherence*. Dove Medical Press Ltd.; 2016. p. 631–40.
- 891 204. Bloom D, Beetsch J, Harker M, Hesterlee S, Moreira P, Patrick-Lake B, et al. The Rules of
892 Engagement. *Ther Innov Regul Sci* [Internet]. 2018 Mar 27 [cited 2019 Jul 18];52(2):206–13.
893 Available from: <http://journals.sagepub.com/doi/10.1177/2168479017720247>
- 894 205. Loudon K, Treweek S, Sullivan F, Donnan P, Thorpe KE, Zwarenstein M. The PRECIS-2 tool:
895 designing trials that are fit for purpose. *BMJ* [Internet]. 2015 May 8 [cited 2020 May
896 6];350:h2147. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25956159>
- 897 206. Australian Clinical Trials Alliance. Toolkit for Researchers and Research Organisations
898 [Internet]. 2019 [cited 2019 Dec 6]. Available from:
899 <https://involvementtoolkit.clinicaltrialsalliance.org.au/toolkit/>
- 900 207. Federal Communications Commission. FCC ID Search [Internet]. [cited 2021 Jan 18]. Available
901 from: <https://fccid.io/>
- 902 208. Mcilduff C, Forster M, Carter E, Davies J, Thomas S, Turner KMT, et al. Model of Engaging
903 Communities Collaboratively. *Int J Crit Indig Stud* [Internet]. 2019 [cited 2020 Sep 2];13(1).
904 Available from: <https://ijcis.qut.edu.au/article/download/1346/948>
- 905 209. Global Environment Facility. Impact Evaluation - Case Study: Bwindi Impenetrable National
906 Park and Mgahinga Gorilla National Park Conservation Project [Internet]. 2007 [cited 2020
907 May 9]. Available from: [https://www.gefio.org/sites/default/files/ieo/ieo-documents/ie-](https://www.gefio.org/sites/default/files/ieo/ieo-documents/ie-bwindi-mgahinga-parks.pdf)
908 [bwindi-mgahinga-parks.pdf](https://www.gefio.org/sites/default/files/ieo/ieo-documents/ie-bwindi-mgahinga-parks.pdf)
- 909 210. Initiative for Open Citations. Initiative for Open Citations (I4OC) [Internet]. 2020 [cited 2020
910 May 6]. Available from: <https://i4oc.org/>
- 911 211. International Organization for Standardization (ISO). ISO - Standards [Internet]. 2020 [cited
912 2020 May 11]. Available from: <https://www.iso.org/standards.html>
- 913 212. Schema. Schema.org [Internet]. 2021 [cited 2021 Feb 4]. Available from: <https://schema.org/>
- 914 213. Husereau D, Drummond M, Petrou S, Carswell C, Moher D, Greenberg D, et al. Consolidated
915 Health Economic Evaluation Reporting Standards (CHEERS) statement. *Bmj* [Internet]. 2013
916 [cited 2019 Sep 18];346:1–6. Available from: [https://www-bmj-](https://www-bmj-com.libproxy.lib.unc.edu/content/bmj/346/bmj.f1049.full.pdf)
917 [com.libproxy.lib.unc.edu/content/bmj/346/bmj.f1049.full.pdf](https://www-bmj-com.libproxy.lib.unc.edu/content/bmj/346/bmj.f1049.full.pdf)

- 918 214. Schägner JP, Brander L, Maes J, Hartje V. Mapping ecosystem services' values: Current
919 practice and future prospects. Vol. 4, Ecosystem Services. Elsevier; 2013. p. 33–46.
- 920 215. Education Endowment Foundation. Evaluation [Internet]. 2020 [cited 2020 May 11]. Available
921 from: [https://educationendowmentfoundation.org.uk/projects-and-evaluation/evaluating-](https://educationendowmentfoundation.org.uk/projects-and-evaluation/evaluating-projects/)
922 [projects/](https://educationendowmentfoundation.org.uk/projects-and-evaluation/evaluating-projects/)
- 923 216. Education Endowment Foundation. SPECTRUM Database [Internet]. [cited 2020 May 11].
924 Available from: [https://educationendowmentfoundation.org.uk/projects-and-](https://educationendowmentfoundation.org.uk/projects-and-evaluation/evaluating-projects/measuring-essential-skills/spectrum-database/)
925 [evaluation/evaluating-projects/measuring-essential-skills/spectrum-database/](https://educationendowmentfoundation.org.uk/projects-and-evaluation/evaluating-projects/measuring-essential-skills/spectrum-database/)
- 926 217. The STARportal | Home [Internet]. [cited 2021 Jan 18]. Available from:
927 <https://starportal.edu.au/>
- 928 218. IDESR. International Database of Education Systematic Reviews [Internet]. [cited 2021 Jan
929 18]. Available from: <https://idesr.org/>
- 930 219. Tikly L. What works, for whom, and in what circumstances? Towards a critical realist
931 understanding of learning in international and comparative education. *Int J Educ Dev*. 2015
932 Jan 1;40:237–49.
- 933 220. About — Atlas of Life [Internet]. [cited 2021 Jan 18]. Available from:
934 <https://atlasoflife.org.au/about-1>
- 935 221. International Tree Foundation. Impact report 2019 [Internet]. [cited 2021 Jan 11]. Available
936 from:
937 [https://web.archive.org/web/20210102220323/https://internationaltreefoundation.org/wp-](https://web.archive.org/web/20210102220323/https://internationaltreefoundation.org/wp-content/uploads/2020/07/Impact-Report-2019-compressed.pdf)
938 [content/uploads/2020/07/Impact-Report-2019-compressed.pdf](https://web.archive.org/web/20210102220323/https://internationaltreefoundation.org/wp-content/uploads/2020/07/Impact-Report-2019-compressed.pdf)
- 939 222. Mackay CML, Schmitt MT. Do people who feel connected to nature do more to protect it? A
940 meta-analysis. *J Environ Psychol*. 2019 Oct 1;65:101323.
- 941 223. DataONE. What is DataONE? [Internet]. 2020 [cited 2020 May 10]. Available from:
942 <https://www.dataone.org/what-dataone>
- 943 224. Port Phillip EcoCentre. Citizen Science Evaluation Rubric [Internet]. 2019. Available from:
944 <https://ecocentre.com/sites/default/files/images/Documents/Programs/Baykeeper/Citizen>
945 [Science Evaluation Rubric v1.1.pdf](https://ecocentre.com/sites/default/files/images/Documents/Programs/Baykeeper/Citizen)
- 946 225. Reed MS, Duncan S, Manners P, Pound D, Armitage L, Frewer L, et al. A common standard for
947 the evaluation of public engagement with research. *Res All* [Internet]. 2018 Jan 25 [cited 2018
948 Jan 30];2(1):143–62. Available from:
949 <http://www.ingentaconnect.com/content/10.18546/RFA.02.1.13>
- 950 226. Maccarthy J, Guerin S, Wilson AG, Dorris ER. Facilitating public and patient involvement in
951 basic and preclinical health research. Salsberg J, editor. *PLoS One* [Internet]. 2019 May 14
952 [cited 2019 Dec 12];14(5):e0216600. Available from:
953 <http://dx.plos.org/10.1371/journal.pone.0216600>
- 954 227. Barber R, Boote JD, Parry GD, Cooper CL, Yeeles P, Cook S. Can the impact of public
955 involvement on research be evaluated? A mixed methods study. *Heal Expect* [Internet]. 2012
956 Sep [cited 2016 May 10];15(3):229–41. Available from:
957 <http://www.ncbi.nlm.nih.gov/pubmed/21324054>
- 958 228. Edelman N, Barron D. Evaluation of public involvement in research: Time for a major re-
959 think? *J Heal Serv Res Policy*. 2016;21(3):209–11.

- 960 229. United Nations. United Nations Evaluation Group (UNEG) [Internet]. 2013. Available from:
961 <https://web.archive.org/web/20190912054509/http://www.uneval.org/document/guidance->
962 documents
- 963 230. The Collaboration for Environmental Evidence. Guidelines and Standards for Evidence
964 Synthesis in Environmental Management [Internet]. 2018 [cited 2020 Aug 24]. Available
965 from: <https://www.environmentalevidence.org/information-for-authors>
- 966 231. Barends E, Rousseau DM, Briner RB. CEBMa center for Evidence-Based Management Rapid
967 Evidence Assessments in Management and Organizations [Internet]. 2017 [cited 2020 May
968 13]. Available from: <https://www.cebma.org/wp-content/uploads/CEBMa-REA-Guideline.pdf>
- 969 232. Her Majesty's Treasury (UK). External Quality Assessment Specification [Internet]. [cited 2020
970 Oct 2]. Available from:
971 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_d](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/204216/eqa_specification.pdf)
972 [ata/file/204216/eqa_specification.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/204216/eqa_specification.pdf)
- 973 233. Royal College of Pathologists of Australasia. RCPAQAP Quality Assurance Programs :
974 RCPAQAP [Internet]. 2020 [cited 2020 Oct 2]. Available from: <https://rcpaqap.com.au/>
- 975 234. IRIS+. IRIS+ Standards [Internet]. 2020. [cited 2020 Apr 27]. Available from:
976 <https://iris.thegiin.org/standards/>
- 977 235. Forest Stewardship Council. Digital Audit Report [Internet]. 2020 [cited 2020 Aug 27].
978 Available from: <https://fsc.org/en/innovation/digital-audit-report#one-standard-format>
- 979 236. Open Geospatial Consortium (OGC). Open Geospatial Consortium Standards [Internet]. 2020
980 [cited 2020 May 13]. Available from: <https://www.ogc.org/docs/is>
- 981 237. Group on Earth Observations. Group on Earth Observations Standards and Interoperability
982 Registry [Internet]. 2020 [cited 2020 May 13]. Available from:
983 https://www.earthobservations.org/gci_sr.shtml
- 984 238. Her Majesty's Treasury (UK). The Online System for Central Accounting and Reporting
985 (OSCAR) User Guide [Internet]. 2020 [cited 2020 Oct 2]. Available from:
986 [https://www.gov.uk/government/publications/the-online-system-for-central-accounting-](https://www.gov.uk/government/publications/the-online-system-for-central-accounting-and-reporting-oscar-user-guide)
987 [and-reporting-oscar-user-guide](https://www.gov.uk/government/publications/the-online-system-for-central-accounting-and-reporting-oscar-user-guide)
- 988 239. Digital Transformation Agency. About the Digital Service Standard [Internet]. 2016 [cited
989 2020 Aug 24]. Available from: [https://www.dta.gov.au/help-and-advice/about-digital-service-](https://www.dta.gov.au/help-and-advice/about-digital-service-standard)
990 [standard](https://www.dta.gov.au/help-and-advice/about-digital-service-standard)
- 991 240. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: An expanded disability status
992 scale (EDSS). *Neurology* [Internet]. 1983 Nov 1 [cited 2021 Jan 18];33(11):1444–52. Available
993 from: <https://n.neurology.org/content/33/11/1444>
- 994 241. Rosen RC, Riley A, Wagner G, Osterloh IH, Kirkpatrick J, Mishra A. The international index of
995 erectile function (IIEF): A multidimensional scale for assessment of erectile dysfunction.
996 *Urology* [Internet]. 1997 Jun [cited 2021 Jan 18];49(6):822–30. Available from:
997 <https://pubmed.ncbi.nlm.nih.gov/9187685/>
- 998 242. South A, Hanley B, Gafos M, Cromarty B, Stephens R, Sturgeon K, et al. Models and impact of
999 patient and public involvement in studies carried out by the Medical Research Council Clinical
1000 Trials Unit at University College London: findings from ten case studies. *Trials* [Internet]. 2016
1001 Dec 29 [cited 2016 Aug 3];17(1):376. Available from:
1002 <http://trialsjournal.biomedcentral.com/articles/10.1186/s13063-016-1488-9>

- 1003 243. Chaplin M, Kirkham JJ, Dwan K, Sloan DJ, Davies G, Jorgensen AL. STrengthening the reporting
1004 of pharmacogenetic studies: Development of the STROPS guideline. PLoS Med [Internet].
1005 2020;17(9). Available from:
1006 [https://journals.plos.org/plosmedicine/article/file?id=10.1371/journal.pmed.1003344&type=](https://journals.plos.org/plosmedicine/article/file?id=10.1371/journal.pmed.1003344&type=printable)
1007 [printable](https://journals.plos.org/plosmedicine/article/file?id=10.1371/journal.pmed.1003344&type=printable)
- 1008 244. Cochrane Methods. Methodological Expectations of Cochrane Intervention Reviews (MECIR)
1009 [Internet]. [cited 2021 Jan 18]. Available from:
1010 <https://community.cochrane.org/sites/default/files/uploads/Version March 2020 Final>
1011 [Online version.pdf](https://community.cochrane.org/sites/default/files/uploads/Version March 2020 Final)
- 1012 245. Cochrane Training. Cochrane Handbook for Systematic Reviews of Interventions [Internet].
1013 2020 [cited 2020 Oct 6]. Available from: <https://training.cochrane.org/handbook/current>
- 1014 246. Coulter A, Ellins JO, Swain D, Clarke A, Heron P, Rasul F, et al. Assessing the quality of
1015 information to support people in making decisions about their health and healthcare Picker
1016 Institute Europe [Internet]. 2006 [cited 2020 Aug 24]. Available from:
1017 [https://web.archive.org/web/20200827051316/https://www.picker.org/wp-](https://web.archive.org/web/20200827051316/https://www.picker.org/wp-content/uploads/2014/10/Assessing-the-quality-of-information-to-support-people-in-makin.pdf)
1018 [content/uploads/2014/10/Assessing-the-quality-of-information-to-support-people-in-](https://web.archive.org/web/20200827051316/https://www.picker.org/wp-content/uploads/2014/10/Assessing-the-quality-of-information-to-support-people-in-makin.pdf)
1019 [makin.pdf](https://web.archive.org/web/20200827051316/https://www.picker.org/wp-content/uploads/2014/10/Assessing-the-quality-of-information-to-support-people-in-makin.pdf)
- 1020 247. Agency for Healthcare Research and Quality. Health Literacy Universal Precautions Toolkit
1021 (Second Edition) [Internet]. 2015 [cited 2020 Aug 24]. Available from:
1022 http://www.ahrq.gov/sites/default/files/publications/files/healthlittoolkit2_4.pdf
- 1023 248. Sheet TIP. Standard 2 : Partnering with Consumers Tip Sheet 5 : Preparing written
1024 information for consumers that is clear , understandable and easy to use.
- 1025 249. Centres for Medicare and Medicaid Services. Toolkit for Making Written Material Clear and
1026 Effective [Internet]. 2020 [cited 2020 Aug 24]. Available from:
1027 [https://www.cms.gov/Outreach-and-](https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index?redirect=/WrittenMaterialsToolkit/)
1028 [Education/Outreach/WrittenMaterialsToolkit/index?redirect=/WrittenMaterialsToolkit/](https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index?redirect=/WrittenMaterialsToolkit/)
- 1029 250. Centers for Disease Control and Prevention. Clear Communication Index [Internet]. 2020
1030 [cited 2020 Aug 24]. Available from: <https://www.cdc.gov/ccindex/>
- 1031 251. National Health and Medical Research Council, NMHRC, National Health and Medical
1032 Research Council. Statement on Consumer and Community Participation in Health and
1033 Medical Research [Internet]. Health and Medical Research National Health and Medical
1034 Research Council. 2016 [cited 2016 Oct 18]. Available from:
1035 [https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-](https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research)
1036 [involvement-health-and-medical-research](https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research)
- 1037 252. National Institute for Health Research. Patient and public involvement in health and social
1038 care research: A handbook for researchers [Internet]. 2014. Available from: [https://www.rds-](https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf)
1039 [yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf](https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf)
- 1040 253. Smits DW, Van Meeteren K, Klem M, Alsem M, Ketelaar M. Designing a tool to support
1041 patient and public involvement in research projects: The Involvement Matrix. Res Invol
1042 Engagem [Internet]. 2020 Jun 16 [cited 2020 Aug 24];6(1):30. Available from:
1043 <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00188-4>
- 1044 254. INVOLVE. Guide on co-producing a research project [Internet]. 2018 [cited 2019 May 8].
1045 Available from: [https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-](https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/)
1046 [research-project/](https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/)

255. Pandya-Wood R, Barron DS, Elliott J. A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards. *Res Involv Engagem* [Internet]. 2017 Dec 4 [cited 2019 Feb 19];3(1):6. Available from: <http://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0058-y>
256. International Classification of Functioning, Disability and Health World Health Organization Geneva ICF ii WHO Library Cataloguing-in-Publication Data International classification of functioning, disability and health : ICF. 2001.
257. Wada M, Sixsmith J, Harwood G, Cosco TD, Fang ML, Sixsmith A. A protocol for co-creating research project lay summaries with stakeholders: guideline development for Canada's AGE-WELL network. *Res Involv Engagem* [Internet]. 2020 Dec 8 [cited 2020 May 10];6(1):1–8. Available from: <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00197-3>
258. Policy Research M. PCORI Dissemination and Implementation Toolkit [Internet]. 2017 [cited 2019 Jul 18]. Available from: <https://www.pcori.org/sites/default/files/PCORI-DI-Toolkit-February-2015.pdf>
259. Nilsen ESE, Myrhaug HTH, Johansen M, Oliver SR, Oxman ADA. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. In: Nilsen ES, editor. *Cochrane Database of Systematic Reviews* [Internet]. Chichester, UK: John Wiley & Sons, Ltd; 2006 [cited 2016 Jun 7]. p. CD004563. Available from: <http://doi.wiley.com/10.1002/14651858.CD004563.pub2>
260. National Health Council. Tackling Representativeness: A Roadmap and Rubric [Internet]. 2018 [cited 2019 Jul 18]. Available from: <https://www.nationalhealthcouncil.org/wp-content/uploads/2019/12/Representativeness in Patient Engagement.pdf>
261. PCORI. The Value of Engagement [Internet]. 2018. Available from: <https://www.pcori.org/about-us/our-programs/engagement/public-and-patient-engagement/value-engagement>
262. Abma TA. Dialogue and deliberation: New approaches to including patients in setting health and healthcare research agendas. *Action Res*. 2019;
263. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Aff* [Internet]. 2013 Feb 2 [cited 2018 Jul 3];32(2):223–31. Available from: <http://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1133>
264. Cochrane Consumers and Communication. Guide to Producing and Sourcing Quality Health Information [Internet]. 2019. Available from: https://latrobe.figshare.com/articles/Guide_to_Producing_and_Sourcing_Quality_Health_Information/8123492
265. Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36) I. Conceptual Framework and Item Selection. Vol. 30. 1992.
266. Australian Government Department of Health. Stakeholder engagement framework [Internet]. 2017 [cited 2020 Apr 27]. Available from: <https://www.health.gov.au/resources/publications/stakeholder-engagement-framework>
267. Anne McKenzie. Barriers to community involvement in health and medical research Researcher perspectives on consumer and community involvement in research: a qualitative study [Internet]. 2016 [cited 2020 Apr 30]. Available from:

- 1091 [https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/barriers_report_finalweb.pdf)
1092 [shape-our-research/barriers_report_finalweb.pdf](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/barriers_report_finalweb.pdf)
- 1093 268. EQUATOR Network. Reporting guidelines [Internet]. [cited 2019 Feb 10]. Available from:
1094 <https://www.equator-network.org/reporting-guidelines/>
- 1095 269. Kaisler R. Patient and public involvement and engagement in research - a “how to” guide for
1096 researchers. 2019; Available from: <https://doi.org/10.5281/zenodo.3515811>
- 1097 270. Simon Denegri. Downloadable definition of the impact of public involvement in health
1098 research [Internet]. 2019 [cited 2019 Jul 8]. Available from:
1099 [https://web.archive.org/web/20190708073125/https://simondenegri.com/2019/07/03/dow-](https://web.archive.org/web/20190708073125/https://simondenegri.com/2019/07/03/downloadable-definition-of-the-impact-of-public-involvement-in-health-research-feat-patients-carers-and-the-public/)
1100 [nloadable-definition-of-the-impact-of-public-involvement-in-health-research-feat-patients-](https://web.archive.org/web/20190708073125/https://simondenegri.com/2019/07/03/downloadable-definition-of-the-impact-of-public-involvement-in-health-research-feat-patients-carers-and-the-public/)
1101 [carers-and-the-public/](https://web.archive.org/web/20190708073125/https://simondenegri.com/2019/07/03/downloadable-definition-of-the-impact-of-public-involvement-in-health-research-feat-patients-carers-and-the-public/)
- 1102 271. NIHR Central Commissioning Facility. Patient and Public Involvement and Engagement Plan
1103 [Internet]. 2019. Available from: [https://www.nihr.ac.uk/documents/about-us/our-](https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/CCF-PPIE-plan-2019-20.pdf)
1104 [contribution-to-research/how-we-involve-patients-carers-and-the-public/CCF-PPIE-plan-](https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/CCF-PPIE-plan-2019-20.pdf)
1105 [2019-20.pdf](https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/CCF-PPIE-plan-2019-20.pdf)
- 1106 272. Canadian Institutes, of Health Research. Patient engagement (Canadian Institutes of Health
1107 Research) [Internet]. 2019 [cited 2019 Jul 18]. Available from: [http://www.cihr-](http://www.cihr-irsc.gc.ca/e/45851.html)
1108 [irsc.gc.ca/e/45851.html](http://www.cihr-irsc.gc.ca/e/45851.html)
- 1109 273. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting
1110 checklists: tools to improve reporting of patient and public involvement in research. 2017
1111 [cited 2017 Aug 3]; Available from:
1112 [https://researchinvolvement.biomedcentral.com/track/pdf/10.1186/s40900-017-0062-](https://researchinvolvement.biomedcentral.com/track/pdf/10.1186/s40900-017-0062-2?site=researchinvolvement.biomedcentral.com)
1113 [2?site=researchinvolvement.biomedcentral.com](https://researchinvolvement.biomedcentral.com/track/pdf/10.1186/s40900-017-0062-2?site=researchinvolvement.biomedcentral.com)
- 1114 274. Canadian Institutes of Health Research. Strategy for Patient-Oriented Research Patient
1115 Engagement Framework [Internet]. 2015 [cited 2020 Apr 30]. Available from: [https://cihr-](https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf)
1116 [irsc.gc.ca/e/documents/spor_framework-en.pdf](https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf)
- 1117 275. Tong A, Synnot A, Crowe S, Hill S, Matus A, Scholes-Robertson N, et al. Reporting guideline for
1118 priority setting of health research (REPRISE). BMC Med Res Methodol. 2019 Dec 28;19(1).
- 1119 276. Arthritis Research Canada, University of British Columbia. Workbook to guide the
1120 development of a Patient Engagement In Research (PEIR) Plan [Internet]. 2018 [cited 2020
1121 Apr 30]. Available from: [http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-](http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf)
1122 [Plan-Guide.pdf](http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf)
- 1123 277. Wright D, Foster C, Amir Z, Elliott J, Wilson R. Critical appraisal guidelines for assessing the
1124 quality and impact of user involvement in research. Heal Expect. 2010 Dec;13(4):359–68.
- 1125 278. Institute for Research and Development (Sri Lanka). Establishing & Sustaining meaningful PPIE
1126 in Sri Lankan Research | Institute for Research & Development [Internet]. 2018 [cited 2020
1127 May 9]. Available from: [https://www.ird.lk/establishing-and-sustaining-meaningful-ppie-in-](https://www.ird.lk/establishing-and-sustaining-meaningful-ppie-in-research-in-srilanka/)
1128 [research-in-srilanka/](https://www.ird.lk/establishing-and-sustaining-meaningful-ppie-in-research-in-srilanka/)
- 1129 279. Claw KG, Anderson MZ, Begay RL, Tsosie KS, Fox K, Garrison NA, et al. A framework for
1130 enhancing ethical genomic research with Indigenous communities. Nature Communications.
1131 2018.
- 1132 280. Viergever RF, Olifson S, Ghaffar A, Terry RF. A checklist for health research priority setting:
1133 Nine common themes of good practice [Internet]. Vol. 8, Health Research Policy and Systems.
1134 BioMed Central; 2010 [cited 2021 Jan 18]. p. 36. Available from: [136](http://health-policy-</p>
</div>
<div data-bbox=)

- 1135 systems.biomedcentral.com/articles/10.1186/1478-4505-8-36
- 1136 281. Concannon TW, Meissner P, Grunbaum JA, McElwee N, Guise J-M, Santa J, et al. A new
1137 taxonomy for stakeholder engagement in patient-centered outcomes research. *J Gen Intern*
1138 *Med* [Internet]. 2012 Aug [cited 2017 Jul 31];27(8):985–91. Available from:
1139 <http://www.ncbi.nlm.nih.gov/pubmed/22528615>
- 1140 282. Cochrane Knowledge Translation Strategy [Internet]. 2017 [cited 2019 Jan 29]. Available
1141 from:
1142 [https://web.archive.org/web/20190704045709/https://community.cochrane.org/sites/default](https://web.archive.org/web/20190704045709/https://community.cochrane.org/sites/default/files/uploads/inline-files/Cochrane%20Knowledge%20Translation%20Strategy%20FINAL%20for%20website.pdf)
1143 [files/uploads/inline-files/Cochrane Knowledge Translation Strategy FINAL for website.pdf](https://web.archive.org/web/20190704045709/https://community.cochrane.org/sites/default/files/uploads/inline-files/Cochrane Knowledge Translation Strategy FINAL for website.pdf)
- 1144 283. Tugwell P, Robinson V, Grimshaw J, Santesso N. Systematic reviews and knowledge
1145 translation. *Bull World Health Organ* [Internet]. 2006 Aug [cited 2019 Jan 29];84(8):643–51.
1146 Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16917652>
- 1147 284. Victorian Comprehensive Cancer Centre. VCCC Toolkit [Internet]. 2019 [cited 2020 Apr 29].
1148 Available from: [https://www.viccompccancerctr.org/about-vccc/consumer-](https://www.viccompccancerctr.org/about-vccc/consumer-engagement/toolkit/)
1149 [engagement/toolkit/](https://www.viccompccancerctr.org/about-vccc/consumer-engagement/toolkit/)
- 1150 285. Scottish Medicines Consortium. A Guide for Patient Group Partners [Internet]. 2015 [cited
1151 2020 Sep 22]. Available from: www.scottishmedicines.org
- 1152 286. EUnetHTA. HTA Core Model [Internet]. [cited 2021 Jan 18]. Available from:
1153 <https://eunetha.eu/hta-core-model/>
- 1154 287. Fredriksson M, Tritter JQ. Disentangling patient and public involvement in healthcare
1155 decisions: why the difference matters. *Sociol Heal Illn*. 2017 Jan 1;39(1):95–111.
- 1156 288. Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (Standards for
1157 QQuality Improvement Reporting Excellence): Revised publication guidelines from a detailed
1158 consensus process. *BMJ Qual Saf* [Internet]. 2016 Dec 1 [cited 2020 Sep 22];25(12):986–92.
1159 Available from: <http://www.squire-statement.org>
- 1160 289. Safer Care Victoria SG of V. A framework for better care and outcomes Partnering in
1161 healthcare [Internet]. 2019 [cited 2020 Apr 30]. Available from:
1162 [https://www.bettersafercare.vic.gov.au/sites/default/files/2019-02/Partnering in healthcare](https://www.bettersafercare.vic.gov.au/sites/default/files/2019-02/Partnering%20in%20healthcare%20framework%202019_WEB.pdf)
1163 [framework 2019_WEB.pdf](https://www.bettersafercare.vic.gov.au/sites/default/files/2019-02/Partnering in healthcare framework 2019_WEB.pdf)
- 1164 290. The Economist Intelligence Unit. The Innovation Imperative: The Future of Drug Development
1165 Part I: Research Methods and Findings [Internet]. 2018 [cited 2020 Apr 30]. Available from:
1166 [https://druginnovation.eiu.com/wp-content/uploads/2018/10/Parexel-innovations-in-drug-](https://druginnovation.eiu.com/wp-content/uploads/2018/10/Parexel-innovations-in-drug-development_V10.pdf)
1167 [development_V10.pdf](https://druginnovation.eiu.com/wp-content/uploads/2018/10/Parexel-innovations-in-drug-development_V10.pdf)
- 1168 291. Moullin JC, Sabater-Hernández D, Fernandez-Llimos F, Benrimoj SI. A systematic review of
1169 implementation frameworks of innovations in healthcare and resulting generic
1170 implementation framework. *Heal Res Policy Syst* [Internet]. 2015 Mar 14 [cited 2020 Sep
1171 22];13(1):16. Available from: [https://health-policy-](https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-015-0005-z)
1172 [systems.biomedcentral.com/articles/10.1186/s12961-015-0005-z](https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-015-0005-z)
- 1173 292. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in
1174 research: a systematic review. *BMC Health Serv Res* [Internet]. 2014;14(1):89. Available from:
1175 <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-89>
- 1176 293. PCORI. PCORI's Stakeholders [Internet]. 2014. [cited 2019 Jan 29]. Available from:
1177 <https://www.pcori.org/about-us/our-programs/engagement/pcoris-stakeholders>

- 1178 294. McKenzie A, R H. Planning for consumer and community Participation in Health and Medical
1179 research: A practical guide for health and medical researchers. 2014; Available from:
1180 [https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf)
1181 [shape-our-research/purple_planning_book_271015.pdf](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/purple_planning_book_271015.pdf)
- 1182 295. Food and Drug Administration (USA). Medical Product Safety Information [Internet]. [cited
1183 2021 Jan 18]. Available from: [https://www.fda.gov/safety/medwatch-fda-safety-information-](https://www.fda.gov/safety/medwatch-fda-safety-information-and-adverse-event-reporting-program/medical-product-safety-information)
1184 [and-adverse-event-reporting-program/medical-product-safety-information](https://www.fda.gov/safety/medwatch-fda-safety-information-and-adverse-event-reporting-program/medical-product-safety-information)
- 1185 296. Association for the Accreditation of Human Research Protection Programs. Standard I-9.
1186 2018; Available from:
1187 [https://web.archive.org/web/20180925010802/https://www.aahrpp.org/TipSheetDownload.](https://web.archive.org/web/20180925010802/https://www.aahrpp.org/TipSheetDownload.ashx?fileName=Standard%20I.9%20(2017-10-04).pdf)
1188 [ashx?fileName=Standard I.9 \(2017-10-04\).pdf](https://web.archive.org/web/20180925010802/https://www.aahrpp.org/TipSheetDownload.ashx?fileName=Standard%20I.9%20(2017-10-04).pdf)
- 1189 297. Safer Care Victoria. Voluntary Assisted Dying report of operations (2018-19) [Internet]. 2019
1190 [cited 2020 Aug 24]. Available from: [https://www.bettersafecare.vic.gov.au/reports-and-](https://www.bettersafecare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-2018-19#goto-download)
1191 [publications/voluntary-assisted-dying-report-of-operations-2018-19#goto-download](https://www.bettersafecare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-2018-19#goto-download)
- 1192 298. Global Indigenous Data Alliance. CARE Principles of Indigenous Data Governance [Internet].
1193 [cited 2021 Jan 18]. Available from: <https://www.gida-global.org/care>
- 1194 299. Central Intelligence Agency (USA). The World Factbook [Internet]. [cited 2020 Sep 24].
1195 Available from: <https://www.cia.gov/library/publications/the-world-factbook/>
- 1196 300. United Nations Evaluation Group. Detail of UNEG Code of Conduct for Evaluation in the UN
1197 system [Internet]. 2008 [cited 2020 May 6]. Available from:
1198 [https://web.archive.org/web/20191102030441/http://www.uneval.org/document/detail/10](https://web.archive.org/web/20191102030441/http://www.uneval.org/document/detail/100)
1199 [0](https://web.archive.org/web/20191102030441/http://www.uneval.org/document/detail/100)
- 1200 301. United Nations Evaluation Group. Detail of UNEG Good Practice Guidelines for Follow up to
1201 Evaluations [Internet]. 2010 [cited 2020 May 6]. Available from:
1202 [https://web.archive.org/web/20180721123543/http://www.uneval.org/document/detail/61](https://web.archive.org/web/20180721123543/http://www.uneval.org/document/detail/610)
1203 [0](https://web.archive.org/web/20180721123543/http://www.uneval.org/document/detail/610)
- 1204 302. United Nations Evaluation Group. Detail of Guidance on Evaluating Institutional Gender
1205 Mainstreaming [Internet]. 2018 [cited 2020 May 6]. Available from:
1206 [https://web.archive.org/web/20181214115712/http://www.uneval.org/document/detail/21](https://web.archive.org/web/20181214115712/http://www.uneval.org/document/detail/2133)
1207 [33](https://web.archive.org/web/20181214115712/http://www.uneval.org/document/detail/2133)
- 1208 303. United Nations Evaluation Group. Detail of Mapping & Review of Evaluation Ethics [Internet].
1209 2019 [cited 2020 May 6]. Available from: <http://www.uneval.org/document/detail/2689>
- 1210 304. United Nations Evaluation Group. Detail of Norms and Standards for Evaluation [Internet].
1211 2016 [cited 2020 May 6]. Available from:
1212 <https://web.archive.org/web/20181115190641/http://uneval.org/document/detail/1914>
- 1213 305. United Nations Evaluation Group. Detail of UNEG Quality Checklist for Evaluation Reports
1214 [Internet]. 2010 [cited 2020 May 6]. Available from:
1215 <https://web.archive.org/web/20190718110339/http://uneval.org/document/detail/607>
- 1216 306. United Nations Evaluation Group. Detail of UNEG Quality Checklist for Evaluation Terms of
1217 Reference and Inception Reports [Internet]. 2010 [cited 2020 May 6]. Available from:
1218 [https://web.archive.org/web/20180320223951/http://www.uneval.org/document/detail/60](https://web.archive.org/web/20180320223951/http://www.uneval.org/document/detail/608)
1219 [8](https://web.archive.org/web/20180320223951/http://www.uneval.org/document/detail/608)
- 1220 307. United Nations Evaluation Group. Professional Peer Review of the UNESCO Evaluation
1221 Function [Internet]. 2020 [cited 2020 May 6]. Available from:

- 1222 <http://www.unevaluation.org/document/detail/2778>
- 1223 308. Wilsdon J, Wilsdon J. The metric tide : independent review of the role of metrics in research
1224 assessment and management. 193 p.
- 1225 309. Organisation for Economic Co-operation and Development. Glossary of Key Terms in
1226 Evaluation and Results Based Management [Internet]. 2002 [cited 2020 May 9]. Available
1227 from: <http://www.oecd.org/dac/2754804.pdf>
- 1228 310. International Aid Transparency Initiative. About the IATI Standard [Internet]. [cited 2020 May
1229 11]. Available from: <https://iatistandard.org/en/about/iati-standard/>
- 1230 311. Department for International Development (UK). Broadening The Range Of Designs And
1231 Methods For Impact Evaluation [Internet]. 2012 [cited 2020 May 9]. Available from:
1232 [https://assets.publishing.service.gov.uk/media/57a08a6740f0b6497400059e/DFIDWorkingPa](https://assets.publishing.service.gov.uk/media/57a08a6740f0b6497400059e/DFIDWorkingPaper38.pdf)
1233 [per38.pdf](https://assets.publishing.service.gov.uk/media/57a08a6740f0b6497400059e/DFIDWorkingPaper38.pdf)
- 1234 312. International Initiative for Impact Evaluation (3ie). Impact Evaluation Glossary [Internet].
1235 2012 [cited 2020 May 9]. Available from:
1236 [https://www.3ieimpact.org/sites/default/files/2018-07/impact_evaluation_glossary_-](https://www.3ieimpact.org/sites/default/files/2018-07/impact_evaluation_glossary_-_july_2012_3.pdf)
1237 [_july_2012_3.pdf](https://www.3ieimpact.org/sites/default/files/2018-07/impact_evaluation_glossary_-_july_2012_3.pdf)
- 1238 313. Mansuri G. Community-Based and -Driven Development: A Critical Review. 2004 [cited 2020
1239 May 9]; Available from: [https://academic.oup.com/wbro/article-](https://academic.oup.com/wbro/article-abstract/19/1/1/1690280?redirectedFrom=fulltext)
1240 [abstract/19/1/1/1690280?redirectedFrom=fulltext](https://academic.oup.com/wbro/article-abstract/19/1/1/1690280?redirectedFrom=fulltext)
- 1241 314. Olken BA. Monitoring corruption: Evidence from a field experiment in Indonesia. *J Polit Econ*.
1242 2007 Apr 19;115(2):200–49.
- 1243 315. Ibanez A, Rao V. The Social Impact of Social Funds in Jamaica: A Mixed-Methods Analysis of
1244 Participation, Targeting, and Collective Action in Community-Driven Development [Internet].
1245 The World Bank; 2003 [cited 2020 May 9]. (Policy Research Working Papers). Available from:
1246 <http://elibrary.worldbank.org/doi/book/10.1596/1813-9450-2970>
- 1247 316. Gibson C, Woolcock M. Empowerment, deliberative development, and local-level politics in
1248 Indonesia: Participatory projects as a source of countervailing power. *Stud Comp Int Dev*.
1249 2008 May 10;43(2):151–80.
- 1250 317. Hentschel J. Contextuality and data collection methods: A framework and application to
1251 health service utilisation. *J Dev Stud*. 1999;35(4):64–94.
- 1252 318. Wilkinson R, Marmot M, Academic Search Complete. Social Determinants of Health: the Solid
1253 Facts. [Internet]. 2nd ed. Copenhagen: World Health Organization; 2003 [cited 2019 Jul 8].
1254 Available from: http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf
- 1255 319. Cheer K, Lui FW, Shibasaki S, Harvey A, Grainger D, Tsey K. The case for a Torres Strait
1256 Islander-driven, long-term research agenda for environment, health and wellbeing. *Aust N Z J*
1257 *Public Health* [Internet]. 2020 Jun 20 [cited 2020 Sep 2];44(3):177–9. Available from:
1258 <https://onlinelibrary.wiley.com/doi/abs/10.1111/1753-6405.12979>
- 1259 320. Public Interest Journalism Initiative. About the Public Interest Journalism Initiative [Internet].
1260 2020 [cited 2020 Sep 24]. Available from: <https://piji.com.au/about-us/>
- 1261 321. Pinnock H, Barwick M, Carpenter CR, Eldridge S, Grandes G, Griffiths CJ, et al. Standards for
1262 Reporting Implementation Studies (StaRI) Statement. *BMJ*. 2017 Mar 6;356.
- 1263 322. Food and Drug Administration (USA). Small Entity Compliance Guide: Current Good

- 1264 Manufacturing Practice in Manufacturing, Packaging, Labeling, or Holding Operations for
1265 Dietary Supplements [Internet]. [cited 2021 Jan 18]. Available from:
1266 [https://www.fda.gov/regulatory-information/search-fda-guidance-documents/small-entity-](https://www.fda.gov/regulatory-information/search-fda-guidance-documents/small-entity-compliance-guide-current-good-manufacturing-practice-manufacturing-packaging-labeling)
1267 [compliance-guide-current-good-manufacturing-practice-manufacturing-packaging-labeling](https://www.fda.gov/regulatory-information/search-fda-guidance-documents/small-entity-compliance-guide-current-good-manufacturing-practice-manufacturing-packaging-labeling)
- 1268 323. Therapeutic Goods Administration. Manufacturing principles for medicinal products
1269 [Internet]. [cited 2021 Jan 18]. Available from:
1270 <https://www.tga.gov.au/publication/manufacturing-principles-medicinal-products>
- 1271 324. International Committee of Medical Journal Editors. Defining the Role of Authors and
1272 Contributors [Internet]. [cited 2019 Mar 18]. Available from:
1273 [http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html)
1274 [role-of-authors-and-contributors.html](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html)
- 1275 325. International Council for Commonality in Blood Banking Automation. What is ISBT 128?
1276 [Internet]. [cited 2020 Sep 30]. Available from:
1277 [https://web.archive.org/web/20200930085254/https://www.iccbba.org/home/isbt-128-](https://web.archive.org/web/20200930085254/https://www.iccbba.org/home/isbt-128-basics/what-is-isbt-128)
1278 [basics/what-is-isbt-128](https://web.archive.org/web/20200930085254/https://www.iccbba.org/home/isbt-128-basics/what-is-isbt-128)
- 1279 326. International Committee Of Medical Journal Editors. Uniform requirements for manuscripts
1280 submitted to biomedical journals: Writing and editing for biomedical publication. J Pharmacol
1281 Pharmacother [Internet]. 2010 [cited 2020 Sep 21];1(1):42. Available from:
1282 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3142758/>
- 1283 327. World Association of Medical Editors. World Association of Medical Editors (WAME)
1284 [Internet]. 2020 [cited 2020 May 6]. Available from: <http://wame.org/about>
- 1285 328. BMJ. Reporting patient and public involvement in research [Internet]. 2019 [cited 2019 Mar
1286 24]. Available from:
1287 [https://www.bmj.com/sites/default/files/attachments/resources/2018/03/PPI_in_Research.](https://www.bmj.com/sites/default/files/attachments/resources/2018/03/PPI_in_Research.pdf)
1288 [pdf](https://www.bmj.com/sites/default/files/attachments/resources/2018/03/PPI_in_Research.pdf)
- 1289 329. Group TS. The SPIRIT Statement [Internet]. 2020 [cited 2020 Sep 21]. Available from:
1290 <https://www.spirit-statement.org/spirit-statement/>
- 1291 330. Therapeutic Goods Administration (TGA). GMP clearance guidance [Internet]. [cited 2021 Jan
1292 18]. Available from: <https://www.tga.gov.au/publication/gmp-clearance-guidance>
- 1293 331. Dubois RW, Lauer M, Perfetto E. When is evidence sufficient for decision-making? A
1294 framework for understanding the pace of evidence adoption. 2013 [cited 2019 Jul
1295 18];2(4):383–91. Available from: www.futuremedicine.com
- 1296 332. Synapse. The book of good practices in Patient Engagement. In 2018 [cited 2019 Jul 18].
1297 Available from: <https://synapse.pfmd.org/book-of-good-practices>
- 1298 333. Spindler P, Lima BS. Editorial: The European Patients Academy on Therapeutic Innovation
1299 (EUPATI) Guidelines on Patient Involvement in Research and Development. Front Med
1300 [Internet]. 2018 Nov 8 [cited 2019 May 26];5:310. Available from:
1301 <https://www.frontiersin.org/article/10.3389/fmed.2018.00310/full>
- 1302 334. Patient Focused Medicine. Patient Focused Medicines Development Book of Good Practices
1303 [Internet]. 2018 [cited 2019 Mar 12]. Available from:
1304 <https://patientfocusedmedicine.org/bogp/book-of-good-practices.pdf>
- 1305 335. McPin Foundation. Research Priorities for Children and Young People’s Mental Health:
1306 Interventions and Services. 2018; Available from: [https://mcpin.org/wp-](https://mcpin.org/wp-content/uploads/2018/11/McPin-Foundation-RPRQ-Main-Report.pdf)
1307 [content/uploads/2018/11/McPin-Foundation-RPRQ-Main-Report.pdf](https://mcpin.org/wp-content/uploads/2018/11/McPin-Foundation-RPRQ-Main-Report.pdf)

- 1308 336. Ennis L, Wykes T. Impact of patient involvement in mental health research: longitudinal
1309 study. *Br J Psychiatry* [Internet]. 2013 Nov 1 [cited 2016 Mar 28];203(5):381–6. Available
1310 from: <http://bjp.rcpsych.org/content/203/5/381>
- 1311 337. France EF, Cunningham M, Ring N, Uny I, Duncan EA, Jepson RG, et al. Improving reporting of
1312 meta-ethnography: The eMERGe reporting guidance. *J Adv Nurs* [Internet]. 2019 May 15
1313 [cited 2020 Sep 22];75(5):1126–39. Available from:
1314 <https://onlinelibrary.wiley.com/doi/abs/10.1111/jan.13809>
- 1315 338. Stockholm International Peace Research Institute. Military Expenditure Database [Internet].
1316 [cited 2021 Jan 18]. Available from: <https://www.sipri.org/databases/milex>
- 1317 339. Stockholm International Peace Research Institute. Arms Industry Database [Internet]. [cited
1318 2021 Jan 18]. Available from: <https://www.sipri.org/databases/armsindustry>
- 1319 340. Stockholm International Peace Research Institute. Arms Transfers Database [Internet]. [cited
1320 2021 Jan 18]. Available from: <https://www.sipri.org/databases/armstransfers>
- 1321 341. Stockholm International Peace Research Institute. Multilateral Peace Operations Database
1322 [Internet]. [cited 2021 Jan 18]. Available from: <https://www.sipri.org/databases/pko>
- 1323 342. Center for Open Science. Center for Open Science Mission [Internet]. 2020 [cited 2020 May
1324 6]. Available from: <https://www.cos.io/about/mission>
- 1325 343. Haddaway NR. Open Synthesis: On the need for evidence synthesis to embrace Open Science.
1326 *Environmental Evidence*. 2018.
- 1327 344. European Union. Indicator Frameworks for Fostering Open Knowledge Practices in Science
1328 and Scholarship [Internet]. 2019 [cited 2020 May 6]. Available from:
1329 [https://doi.org/10.2777/445286%0Ahttps://op.europa.eu/en/publication-detail/-](https://doi.org/10.2777/445286%0Ahttps://op.europa.eu/en/publication-detail/-/publication/b69944d4-01f3-11ea-8c1f-01aa75ed71a1/language-en/format-PDF/source-108756824)
1330 [/publication/b69944d4-01f3-11ea-8c1f-01aa75ed71a1/language-en/format-PDF/source-](https://doi.org/10.2777/445286%0Ahttps://op.europa.eu/en/publication-detail/-/publication/b69944d4-01f3-11ea-8c1f-01aa75ed71a1/language-en/format-PDF/source-108756824)
1331 [108756824](https://doi.org/10.2777/445286%0Ahttps://op.europa.eu/en/publication-detail/-/publication/b69944d4-01f3-11ea-8c1f-01aa75ed71a1/language-en/format-PDF/source-108756824)
- 1332 345. OCSDNET. Open Science Manifesto [Internet]. [cited 2020 Apr 28]. Available from:
1333 <https://ocsdnet.org/manifesto/open-science-manifesto/>
- 1334 346. European Commission. Open science monitor [Internet]. 2020 [cited 2020 May 6]. Available
1335 from: [https://ec.europa.eu/info/research-and-innovation/strategy/goals-research-and-](https://ec.europa.eu/info/research-and-innovation/strategy/goals-research-and-innovation-policy/open-science/open-science-monitor_en)
1336 [innovation-policy/open-science/open-science-monitor_en](https://ec.europa.eu/info/research-and-innovation/strategy/goals-research-and-innovation-policy/open-science/open-science-monitor_en)
- 1337 347. Zooniverse. Zooniverse [Internet]. 2020 [cited 2020 May 6]. Available from:
1338 <https://www.zooniverse.org/about>
- 1339 348. Todd MH. Six Laws of Open Source Drug Discovery. *ChemMedChem* [Internet]. 2019 Nov 6
1340 [cited 2020 May 6];14(21):1804–9. Available from:
1341 <https://onlinelibrary.wiley.com/doi/abs/10.1002/cmdc.201900565>
- 1342 349. Patient Engagement Monitoring and Evaluation Framework with metrics [Internet]. [cited
1343 2020 Sep 23]. Available from: <https://imi-paradigm.eu/petoolbox/>.
- 1344 350. Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research:
1345 Moving from theory to practice. Vol. 4, *Journal of Comparative Effectiveness Research*.
1346 Future Medicine Ltd.; 2015. p. 133–45.
- 1347 351. OpenID Foundation. OpenID Self-Certification. 2015.
- 1348 352. Parker L, Fabbri A, Grundy Q, Mintzes B, Bero L. “asset exchange” - Interactions between
1349 patient groups and pharmaceutical industry: Australian qualitative study. *BMJ*. 2019;367.

- 1350 353. UK Government. Test, Learn, Adapt: Developing Public Policy with Randomised Controlled
1351 Trials. 2012; Available from: [https://www.gov.uk/government/publications/test-learn-adapt-](https://www.gov.uk/government/publications/test-learn-adapt-developing-public-policy-with-randomised-controlled-trials)
1352 [developing-public-policy-with-randomised-controlled-trials](https://www.gov.uk/government/publications/test-learn-adapt-developing-public-policy-with-randomised-controlled-trials)
- 1353 354. What Works UK. The Rise of Experimental Government: Cross-Government Trial Advice Panel
1354 Update Report [Internet]. 2018 [cited 2020 May 11]. Available from:
1355 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_d](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/753468/RiseExperimentalGovernment_Cross-GovTrialAdvicePanelUpdateReport.pdf)
1356 [ata/file/753468/RiseExperimentalGovernment_Cross-GovTrialAdvicePanelUpdateReport.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/753468/RiseExperimentalGovernment_Cross-GovTrialAdvicePanelUpdateReport.pdf)
- 1357 355. Nesta. Using research evidence: A Practice Guide [Internet]. 2016 [cited 2020 May 13].
1358 Available from: www.alliance4usefulevidence.org/join
- 1359 356. Gaudet J. Unfolding the map: Making knowledge and ignorance mobilization dynamics visible
1360 in science evaluation and policymaking. In: Routledge International Handbook of Ignorance
1361 Studies. 2015.
- 1362 357. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of good
1363 practice for the translation and cultural adaptation process for patient-reported outcomes
1364 (PRO) measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation.
1365 Value Heal [Internet]. 2005 [cited 2021 Jan 18];8(2):94–104. Available from:
1366 <https://pubmed.ncbi.nlm.nih.gov/15804318/>
- 1367 358. Product Safety Australia. About mandatory standards [Internet]. 2020 [cited 2020 Aug 24].
1368 Available from: [https://www.productsafety.gov.au/product-safety-laws/safety-standards-](https://www.productsafety.gov.au/product-safety-laws/safety-standards-bans/mandatory-standards/about-mandatory-standards#safety-criteria)
1369 [bans/mandatory-standards/about-mandatory-standards#safety-criteria](https://www.productsafety.gov.au/product-safety-laws/safety-standards-bans/mandatory-standards/about-mandatory-standards#safety-criteria)
- 1370 359. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for
1371 characterising and designing behaviour change interventions. Implement Sci. 2011 Apr
1372 23;6(1).
- 1373 360. The Behavioural Insights Team, Service O, Hallsworth M, Halpern D, Algate F, Gallagher R, et
1374 al. EAST Four simple ways to apply behavioural insights [Internet]. 2014 [cited 2020 Apr 30].
1375 Available from: [https://www.bi.team/wp-content/uploads/2015/07/BIT-Publication-](https://www.bi.team/wp-content/uploads/2015/07/BIT-Publication-EAST_FA_WEB.pdf)
1376 [EAST_FA_WEB.pdf](https://www.bi.team/wp-content/uploads/2015/07/BIT-Publication-EAST_FA_WEB.pdf)
- 1377 361. Kneebone S, Smith L, Fielding K. The Impact-Likelihood Matrix: A policy tool for behaviour
1378 prioritisation. Environ Sci Policy. 2017 Apr 1;70:9–20.
- 1379 362. Crossref. Crossref [Internet]. 2020 [cited 2020 May 6]. Available from:
1380 <https://www.crossref.org/>
- 1381 363. Committee on Publication Ethics. Committee on Publication Ethics [Internet]. 2020 [cited
1382 2020 May 6]. Available from: <https://publicationethics.org/about/our-organisation>
- 1383 364. Committee on Publication Ethics. Guidance for Editors: research, audit and service
1384 evaluations [Internet]. 2014 [cited 2020 May 6]. Available from:
1385 [https://publicationethics.org/files/Guidance_for_Editors_Research_Audit_and_Service_Evalu](https://publicationethics.org/files/Guidance_for_Editors_Research_Audit_and_Service_Evaluations_v2_0.pdf)
1386 [ations_v2_0.pdf](https://publicationethics.org/files/Guidance_for_Editors_Research_Audit_and_Service_Evaluations_v2_0.pdf)
- 1387 365. Committee on Publication Ethics. Principles of Transparency and Best Practice in Scholarly
1388 Publishing [Internet]. 2014 Jan [cited 2020 May 6]. Available from:
1389 <https://publicationethics.org/node/19881>
- 1390 366. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative
1391 Research. Acad Med [Internet]. 2014 Sep [cited 2019 Nov 11];89(9):1245–51. Available from:
1392 [http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00001888-](http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00001888-201409000-00021)
1393 [201409000-00021](http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00001888-201409000-00021)

- 1394 367. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ):
1395 a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* [Internet]. 2007 Sep
1396 16 [cited 2019 Nov 11];19(6):349–57. Available from:
1397 <https://academic.oup.com/intqhc/article-lookup/doi/10.1093/intqhc/mzm042>
- 1398 368. Schulz KF, Altman DG, Moher D. coNSort 2010 Statement: updated guidelines for reporting
1399 parallel group randomised trials. *BMJ* [Internet]. 2010 [cited 2019 Jan 29];340:332. Available
1400 from: www.consort-statement.org
- 1401 369. Department of Environment, Land, Water and Planning, Victorian Government A. DELWP
1402 Output data standards [Internet]. Available from:
1403 [water.vic.gov.au/__data/assets/pdf_file/0016/120463/DELWP-OutputDataStandard-web-](http://water.vic.gov.au/__data/assets/pdf_file/0016/120463/DELWP-OutputDataStandard-web-V4.0.pdf)
1404 [V4.0.pdf](http://water.vic.gov.au/__data/assets/pdf_file/0016/120463/DELWP-OutputDataStandard-web-V4.0.pdf)
- 1405 370. RAID. Research Activity Identifier [Internet]. 2018 [cited 2019 Jul 7]. Available from:
1406 <https://www.raid.org.au/>
- 1407 371. Australian Commission on Safety and Quality in Health Care. Partnering with Consumers
1408 Standards [Internet]. 2011. Available from:
1409 [https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-](https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard#criteria)
1410 [standard#criteria](https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard#criteria)
- 1411 372. Richard Gold E, Ali-Khan SE, Allen L, Ballell L, Barral-Netto M, Carr D, et al. Gates Open
1412 Research An open toolkit for tracking open science partnership implementation and impact
1413 [version 1; peer review: awaiting peer review]. *Dis Dev World* [Internet]. 2019 [cited 2019
1414 May 26]; Available from: <https://doi.org/10.12688/gatesopenres.12958.1>
- 1415 373. Directory of Open Access Journals. Directory of Open Access Journals [Internet]. 2020 [cited
1416 2020 May 6]. Available from: <https://doaj.org/about>
- 1417 374. European Association of Science Editors. EASE Guidelines for Authors and Translators of
1418 Scientific Articles to be Published in English. 2018 [cited 2020 May 6]; Available from:
1419 www.ease.org.uk
- 1420 375. Open Access Scholarly Publishers Association. Open Access Scholarly Publishers Association
1421 Mission [Internet]. 2020 [cited 2020 May 6]. Available from:
1422 <https://oaspa.org/about/mission-and-purpose/>
- 1423 376. Council of Science Editors. Promoting Integrity in Scientific Journal Publications - Council of
1424 Science Editors [Internet]. 2009 [cited 2020 May 6]. Available from:
1425 [https://druwt19tzv6d76es3lg0qdo7-wpengine.netdna-ssl.com/wp-content/uploads/CSE-](https://druwt19tzv6d76es3lg0qdo7-wpengine.netdna-ssl.com/wp-content/uploads/CSE-White-Paper_2018-update-050618.pdf)
1426 [White-Paper_2018-update-050618.pdf](https://druwt19tzv6d76es3lg0qdo7-wpengine.netdna-ssl.com/wp-content/uploads/CSE-White-Paper_2018-update-050618.pdf)
- 1427 377. Council of Science Editors. Scientific style and format : the CSE manual for authors, editors,
1428 and publishers. 722 p.
- 1429 378. WikiJournal User Group. WikiJournal User Group Ethics statement [Internet]. 2020 [cited
1430 2020 May 6]. Available from:
1431 https://en.wikiversity.org/wiki/WikiJournal_User_Group/Ethics_statement
- 1432 379. Citizen Science Association (USA). About the Public Participation in Scientific Research (PPSR)
1433 Core metadata standards repository [Internet]. 2020 [cited 2020 Oct 2]. Available from:
1434 <https://github.com/CitSciAssoc/DMWG-PPSR-Core/wiki/About-the-PPSR-Core>
- 1435 380. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for
1436 scoping reviews (PRISMA-ScR): Checklist and explanation. Vol. 169, *Annals of Internal*
1437 *Medicine*. American College of Physicians; 2018. p. 467–73.

- 1438 381. International Social and Environmental Accreditation and Labelling Alliance. Assessing the
1439 Impacts of Social and Environmental Standards Systems ISEAL Code of Good Practice
1440 [Internet]. 2014 [cited 2020 Aug 27]. Available from: [www.isealliance.org/our-](http://www.isealliance.org/our-work/defining-credibility/)
1441 [work/defining-credibility/](http://www.isealliance.org/our-work/defining-credibility/)
- 1442 382. International Social and Environmental Accreditation and Labelling Alliance. ISEAL is the
1443 global membership organisation for credible sustainability standards [Internet]. 2020 [cited
1444 2020 Aug 27]. Available from: <https://www.isealliance.org/>
- 1445 383. Social Care Institute for Excellence. Co-production in social care: What it is and how to do it
1446 [Internet]. 2015 [cited 2020 May 6]. Available from:
1447 <https://www.scie.org.uk/publications/guides/guide51/files/guide51-easyread.pdf>
- 1448 384. Brazma A, Hingamp P, Quackenbush J, Sherlock G, Spellman P, Stoeckert C, et al. Minimum
1449 information about a microarray experiment (MIAME) - Toward standards for microarray data.
1450 Vol. 29, Nature Genetics. 2001. p. 365–71.
- 1451 385. Forest Stewardship Council. Data Standard Report with International Social and
1452 Environmental Accreditation and Labelling Alliance [Internet]. 2020 [cited 2020 Aug 27].
1453 Available from: <https://fsc.org/en/innovation/data-standard-report>
- 1454 386. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the
1455 synthesis of qualitative research: ENTREQ. BMC Med Res Methodol [Internet]. 2012 Dec 27
1456 [cited 2020 Sep 22];12(1):181. Available from:
1457 <https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-12-181>
- 1458 387. Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication
1459 standards: Realist syntheses. BMC Med [Internet]. 2013 Jan 29 [cited 2020 Sep 22];11(1):1–
1460 14. Available from: <https://link.springer.com/articles/10.1186/1741-7015-11-21>
- 1461 388. Wong G, Westhorp G, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh T. RAMESES II
1462 reporting standards for realist evaluations. BMC Med [Internet]. 2016 Jun 24 [cited 2020 Sep
1463 22];14(1):1–18. Available from: [https://link.springer.com/articles/10.1186/s12916-016-0643-](https://link.springer.com/articles/10.1186/s12916-016-0643-1)
1464 [1](https://link.springer.com/articles/10.1186/s12916-016-0643-1)
- 1465 389. Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, et al. Development of the ACTIVE
1466 framework to describe stakeholder involvement in systematic reviews. J Health Serv Res
1467 Policy [Internet]. 2019 Apr 18 [cited 2019 Apr 28];135581961984164. Available from:
1468 <http://journals.sagepub.com/doi/10.1177/1355819619841647>
- 1469 390. Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, et al. Stakeholder involvement in
1470 systematic reviews: a scoping review. Syst Rev. 2018 Nov 24;7(1).
- 1471 391. Cochrane. PROGRESS-Plus [Internet]. [cited 2019 Jul 8]. Available from:
1472 <https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus>
- 1473 392. CITES. Checklist of CITES species [Internet]. 2020 [cited 2020 Oct 2]. Available from:
1474 <https://checklist.cites.org/#/en>
- 1475 393. Inglehart R. Mapping global values. Comp Sociol. 2006 Jun 1;5(2–3):115–36.
- 1476 394. BMC. Research Involvement and Engagement - Reporting standards [Internet]. Research
1477 Involvement and Engagement. 2019 [cited 2019 Feb 5]. Available from:
1478 [https://researchinvolvement.biomedcentral.com/submission-guidelines/preparing-your-](https://researchinvolvement.biomedcentral.com/submission-guidelines/preparing-your-manuscript/research)
1479 [manuscript/research](https://researchinvolvement.biomedcentral.com/submission-guidelines/preparing-your-manuscript/research)
- 1480 395. International Association for Public Participation. Participation Spectrum [Internet]. 2014

1481 [cited 2018 Jul 12]. Available from:
1482 [https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spect](https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spectrum.pdf)
1483 [rum.pdf](https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spectrum.pdf)
1484