From “wading through treacle” to “making haste, slowly” in patient data sharing:

A comprehensive yet parsimonious model of drivers and challenges to data sharing

based on an EPaCCS evaluation and four pre-existing literature reviews

Mila Petrova and Stephen Barclay

Short title: Drivers and challenges to patient data sharing

Dr Mila Petrova (corresponding author)

mp686@medschl.cam.ac.uk

Visiting Fellow, Palliative and End of Life Care Group in Cambridge (PELiCam), Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, UK

Dr Stephen Barclay

sigb2@medschl.cam.ac.uk

Palliative and End of Life Care Group in Cambridge (PELiCam), Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, UK

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ABSTRACT

Aims: This study aimed to identify comprehensively the challenges and drivers encountered by Electronic Palliative Care Coordination System (EPaCCS) projects in the context of challenges and drivers in other projects on data sharing for individual care (also referred to as Health Information Exchange, HIE). It aimed to organise them in a parsimonious framework that underpins specific and non-trivial recommendations for steps forward.

Data and methods: Primary data comprised 40 in-depth interviews with healthcare professionals from general practice, out-of-hours, specialist palliative care and hospital services; patients and carers; project team members and decision makers in Cambridgeshire, UK. Transcripts amounted to approximately 300,000 words. Secondary data were extracted from four pre-existing literature reviews on Health Information Exchange and Health Information Technology implementation covering 135 studies. A seven-stage analysis process was employed.

Results: We reduced an initial set of >1,800 parameters into >500 challenges and >300 drivers to implementing EPaCCS and other data sharing projects. Less than a quarter of the 800+ parameters were associated primarily with the IT solution. These challenges and drivers were further condensed into an action-guiding, strategy-informing framework of nine types of “pure challenges”, drawing parallels between patient data sharing and other broad and complex domains of sociotechnical or social practice; four types of “pure drivers”, defined in terms of whether they were internal or external to the IT solution and project team; and nine types of “oppositional or ambivalent forces”, representing factors perceived simultaneously as a challenge and a driver.

Conclusions: Teams working on data sharing projects may need to focus less on refining their IT tools and more on shaping the social interactions and structural and contextual parameters in the midst of which they are configured. The high number of “ambivalent forces” speaks of the vital importance for data sharing projects of skills in eliciting stakeholders’ assumptions; managing conflict; and navigating multiple needs, interests and “worldviews”, amongst others.

AUTHOR SUMMARY

Sharing data is often effortless in our everyday lives. As a result, many patients assume that there are robust systems and processes for sharing their medical records and other data about their health, diseases and treatments. This is hardly the case. Patient data sharing systems are notoriously difficult to design, implement and sustain. Moreover, while the benefits of using them appear self-evident and significant, the evidence in their favour is uncertain. In this paper, we bring together evidence on the challenges and drivers to patient data sharing, as coming from 40 in-depth interviews (approximately 300,000 words) with health professionals, IT experts, decision makers, patients and carers involved in a data sharing project in England, as well as findings from four literature reviews covering 135 studies. We condense an initial set of 1,800 challenges and drivers into a set of 800+ parameters and, ultimately, a 22-component framework offering new ways of seeing and moving forward with patient data sharing. Most crucially, we find that about three-quarters of the 800+ challenges and drivers are unrelated to the technological solution. Some of the social and psychological barriers to patient data sharing are far more intractable than the technological ones.

INTRODUCTION

Patient data sharing is a concept of multiple meanings and associated beliefs and values, including in terms of the seemingly basic fact of whether it is a daily reality, troubled possibility, or soon-to-be-available-golden-opportunity. Most patients take the appropriate sharing of their health-related information for granted. It is an incomprehensible failure of healthcare systems or staff if it has not been done as and when needed. In the inspirational narratives of developers, entrepreneurs, start-up owners and policy makers, patient data sharing is a door to a treasure trove of knowledge. It is on the brink of being unlocked, with a world of opportunity for radically improving people's health and healthcare right behind it. For most health professionals, however, patient data sharing is a broken promise or one that has been grossly under-delivered to, for many more times and many more years than they can easily count.

The complexity around the basics of patient data sharing is exacerbated by the language we use. Two closely interconnected but also distinctly different forms of patient data sharing have a shared vocabulary, at least in a UK context (the context of this study). Some data sharing is only or primarily for "individual care". This use appears synonymous with Health Information Exchange, with the term more popular in the US [1]. Other data sharing is for "improving health, care and services through research and planning" [2]. This drive may overlap significantly with the drive for "open data", "open science" and "open access", yet data for improving health, care and services through research and planning may not be open at all.

This paper does not aim to address the above complexity. It points it out as a background to its focus on *data sharing for individual care*. We will often shorten the phrase to “data sharing”, as typical in a UK context. We will also use the term interchangeably with Health Information Exchange (HIE), as it appears in much of the US and international literature we have accessed. We follow a loose definition as per which data sharing for individual care/health information exchange “allows doctors, nurses, pharmacists, other health care providers and patients to appropriately access and securely share a patient’s vital medical information electronically—improving the speed, quality, safety and cost of patient care” [1].

Some of the key theoretical benefits of data sharing for individual care, which are only partially supported by inconclusive and generally low quality evidence, include: improved clinical decision making [3,4], patient safety [5-11], and coordination and continuity of care[12-14]; reduction in duplicate investigations [3, 15-20] and hospital admissions [3, 19-25]; holistic management of complex cases [26-28]; enhanced patient experience, involvement, empowerment and activation [11,29,30]; and, importantly, cost-savings [16, 19, 20, 31-34]. Yet despite the indicative evidence, persuasiveness of the logic models, ever growing sophistication of the technology, and significant investment in health IT [35-37], data sharing solutions face substantial challenges of development, implementation, uptake, sustainable use, and robustly demonstrated impact. They often fail to live up to expectations or straightforwardly fail [32, 38-49]. According to the systematic review of Rudin et al. [32], HIE tools are typically used in 2% to 10% of patient visits and their impact on outcomes is largely unknown beyond probable reduction of emergency department usage and costs in some cases. A more recent review [50] leans towards more positive

conclusions, reporting that 60% (15) of the included studies demonstrated positive financial effects and 64% (16) facilitated quality improvement, but it recognises the overall low quality of evidence.

Aims, objectives and methods in brief

We present a comprehensive yet parsimonious model of drivers and challenges to patient data sharing, drawing on the qualitative arm of an evaluation of a flagship data sharing project in England – the Cambridgeshire and Peterborough Clinical Commissioning Group (CCG) Project for Data Sharing in End of Life Care (herebelow referred to as “the EoLC data sharing project”) – and cumulative evidence from four pre-existing literature reviews [32,41,51,52]. The evaluated project was an Electronic Palliative Care Coordination System (EPaCCS), one of the major developments in England’s palliative and end of life care, underway since 2008 [53]. The primary data for the qualitative arm of the evaluation consisted of 40 interviews with 45 participants, including project developers (6), data sharing initiators (General Practitioners, 7); data sharing recipients (out-of-hours staff, palliative care specialists, hospital staff, administrator, 15); data sharing beneficiaries (patient and carers, 9), and representatives of the broader project context/ local health economy (8). The approximate word count for the interviews was 300,000 words. The four literature reviews were on the implementation, uptake (adoption, usage), and effectiveness of health information technology (HIT) and health information exchange and encompassed 135 studies.[32,41,51,52]

Following a 7-stage iterative analysis process, we condensed over 1,800 challenges and drivers into a framework of 22 action-guiding categories. These include nine categories of

“pure challenges”, four categories of “pure drivers”, and nine categories of “oppositional and/or ambivalent forces”, as represented in the Results section below. Despite numerous stages of filtering down the original 1,800 parameters, the paper is of above average length (over 11,000 words excluding quotes and Materials and Methods). We sought to facilitate reading and retention through a clear structure, the use of “catchy” popular culture metaphors and/or mnemonics for most categories of challenges and drivers, and through minimising well-known claims in the literature on health information technology. Conceptual descriptions are accompanied by illustrative quotes. Quotes by members of the core project team or the broad project network have no indicator of source, as most roles are uniquely identifiable in the locality. Quotes representing conflict or substandard work are also left unattributed throughout the paper.

Further methodological detail is provided at the end of the paper (Materials and Methods) and in Supplementary file 1 (S1).

RESULTS

1. PURE CHALLENGES

We formulated nine sources of pure challenges to patient data sharing along the lines of:

- 1) broad and complex domains of social or sociotechnical practice of which health IT is only one, and recent, example. For example, health IT is a “radical innovation”, but so were building the railways or developing the aviation industry in their time;

2) pairs of endeavours or entities often thought of as natural contrasts (e.g. humans – machines, specialists – non-specialists).

Challenges were designated as “pure challenges” if the interviewees discussed them without mentioning an effective counteracting driver. The lack of a clear enough positive counterpoint did not mean that nothing was being done or could be done about them. Rather, actors were perceiving such challenges, in the (then) current state of development of health IT, as immensely complex, potentially intractable issues, able to “kill” a data sharing project, while being largely outside of the scope of influence of the project team.

1.1. Radical innovation challenges (“I Saved the World Today”)

1.1.1. Magnitude of repetition (“Banality of evil”)

A key reason why radical innovation projects fail, become stymied, or advance arduously slowly, even if the solution they are offering is compelling, is the immense magnitude of repetition involved. This concerns both entities for which the underpinning infrastructure needs to be set up (settings, teams, computers) and individuals whose behaviours and mentality need to be modified. The multiplicity of entities and individuals is also a reason why the same project can appear, or be presented, as both remarkably successful and seriously failing. Numbers reached can be striking as raw numbers yet represent a tiny proportion of all relevant entities and individuals.

Numerous demanding and time-intensive tasks, actions and micro-projects as well as many minor but indispensable tasks need to be repeated across entities. Examples of such work in the EoLC data sharing project included (the list is non-exhaustive):

- 167 ○ “persuading” organisations to take part;
- 168 ○ negotiating the parameters of their involvement in the context of omnipresent
- 169 conflicting demands and opportunities;
- 170 ○ the signing of Information Governance (IG) agreements with each participating
- 171 organisation;
- 172 ○ configuring the systems of each organisation and, sometimes, every computer within
- 173 the organisation;
- 174 ○ developing setting-specific launch activities and communications;
- 175 ○ training of staff;
- 176 ○ tailoring aspects of the IT solution to the needs of each organisation;
- 177 ○ negotiating continued involvement in cases when such tailoring was problematic;
- 178 ○ reaching agreements on standardised symbols.

179

180 Much of this work was expected to be owned by to the project *users*, but this was either not
181 the case or it needed to be initiated, facilitated, coordinated and monitored by the data
182 sharing project team. Not infrequently, tasks which were expected to be user-owned were
183 taken up by members of the project team outside of their lines of duty, as this was the only
184 way to advance the project.

185

186 Some of the minor repetitive or small variations tasks were experienced as particularly
187 frustrating and often unnecessary. Yet such work could also dramatically increase uptake
188 (e.g. if an organisational target or incentive was added to the data sharing template) or be
189 indispensable for patient safety (e.g. because a different local use of the same symbol could
190 trigger the wrong pathway).

191 So we get eight different MDT [multidisciplinary team coordinator] projects instead of an
192 MDT project with perhaps a little bit of local variation. It very much feels that you get
eight different ones.

193 *Interviewee 1:* Some people call them a red star patient, some people call them
194 vulnerable, there's lots of different names for them and you're trying to work out what
they are then [unfinished]

195 *Interviewee 2:* In [GP practice] a red star patient is a violent or aggressive patient.

196 *Interviewee 1:* 'What's [whispers] a green star patient ...?'. It came up on the home page,
197 green star, I thought, end of life, is this cancer, what, what is it? [*Interviewee 1 – Out of*
198 *hours professional 1, Nurse*]

199 The work also becomes mundane, while most individuals working on innovation are drawn
200 to the excitement, creativity and buzz associated with it.

201 I enjoy new things, so any new project is exciting. ... But then, after a while, if the service is
202 up and running, it becomes about performance management, and that is a bit repetitive,
really.

203 For some services, it is a drag, it doesn't run ... and you'll have to re-adjust, re-educate,
204 resend out communications, begging your stakeholders ... 'you're not using it, you asked
205 for it and now it's here, you're not using it!'.
206

207 In some settings, the diffusion of innovation relied on a single individual and was thus
208 entirely dependent on their continued employment or capacity.

209 1.1.2. Alternatives (“1001 nITes”)

210 A further frequently mentioned challenge within the radical innovation category concerned
211 the range of alternative tools and workflows available or under development. Between
212 themselves and unprompted by a specific question in the interview schedule, the
213 interviewees identified 13 types of alternatives to the EoLC data sharing tools, whether

214 EoLC-specific, generic but incorporating end of life care, or “other”. Most of these
215 alternatives were standard practice in some organisations and workflows:

- 216 1. letters (generic and suitable for EoLC);
- 217 2. handover forms for the out-of-hours service (generic and suitable for EoLC);
- 218 3. direct communication with patients, family and colleagues (generic and suitable for
219 EoLC);
- 220 4. patient-held EoLC information (initiative known as “the yellow folder”);
- 221 5. own EoLC templates for internal sharing within a setting or team;
- 222 6. generic sharing within the clinical IT system which underpins the EoLC data sharing;
- 223 7. national data sharing work, such as the Summary Care Record (generic with an EoLC-
224 specific module);
- 225 8. commercial products (generic, some with an EoLC-specific module);
- 226 9. other local data sharing work underway, at that time early prototypes of the Local
227 Health and Care Records (generic, availability of EoLC module unclear);
- 228 10. other active local data sharing projects aiming to engage the acute services,
229 particularly Accident & Emergency departments, e.g. as developed by the police or
230 mental health trust (little relevance to EoLC);
- 231 11. routine data extraction projects for (national) reporting, monitoring, research and
232 evaluation purposes;
- 233 12. structured Word-based forms for collecting and summarising information in EoLC,
234 such as for advance care planning; and
- 235 13. highly specific forms covering a single but key aspect of EoLC, such as Do Not
236 Attempt Cardiopulmonary Resuscitation (DNACPR) forms.

237

238 Many of these alternatives also had subtypes or periodically updated versions. The
239 interviewees did not single out any such alternative as consistently better than the EoLC
240 data sharing project (or any other alternative, for that matter), but most were spoken of as
241 having some major advantages; as being the natural thing to do, embedded in current
242 workflows; as the “go-to” option for communication with some settings (e.g. DNACPR forms
243 emailed to the Ambulance Service); or as an attractive new opportunity to explore.

244 Together, however, they contributed to confusion, frustration and refusal to engage in
245 certain types of data sharing, end of life care work or work at the intersection of the two.

246 I don’t do hospitals, I have got a yellow folder which is known to the ambulance men and
247 paramedics, that’s all my notes and everything about me is all written in that folder ... and I
keep that in the bedroom.

248 [L]ast year, when we had an out-of-hours doctor come, it was useful for him to look at it
because although he’d got his laptop, he could look up things, it was as easy to look in the
249 book and see what was relevant. *[Patient 1]*

250 [Some practices] are happy to take on the tools that we’re providing for them and others are
saying, “no, we’ve got our own system, we don’t wanna use that”.

251 I talked to their IT man ... who is responsible for producing parts of the [new provider]
252 solution, which is a single view of the record. ... I’m just trying to discourage him from
launching a single view record on the 1st April that only has in it the drugs and the problem
253 list and allergies, because that’s all he can deliver on the 1st of April.

254 [A]t the nursing home, they have their own DNR forms they want, which I’m kind of refusing
255 to sign, I’m just doing those red-edged boxed ones. *[GP 7]*

256

257 1.1.3. *Vicious circles (“Catch 22s”)*

258 Radical innovation work also needs to break away from a range of *prima facie* paradoxical
259 situations, irresolvable dilemmas, vicious circles or “chicken-and-egg” conundrums. For
260 instance, users of the data sharing project in acute settings needed to see quick positive
261 results from their engagement with the community system, while community healthcare

262 staff needed to see positive action from acute settings in order to keep sharing data.

263 Similarly, users were prone to give up quickly due to disappointment with a tool, while

264 developers needed initial grace, continued engagement and constructive feedback:

265

266 [O]bviously, the information has to be on it for, I don't know, what do you think [turns to second interviewee], 90% of the patients? *[Palliative care professional 1]*

267 [I]f the special note or whatever is not picked up by 111 or the ambulance trust and then suddenly

268 you have a GP saying, "Well, I had this patient, we did all this and then anyway, they end up [in hospital]. So, obviously, why are we filling this in if it's not actually looked at?!"

269 I say to them, "Please have a look at the things. You'll probably find some of them useless. Tell us

270 and we will improve the quality of it. But if you don't start to use it, then we're wasting all our time in the community entering the data".

271

272 Several interviewees highlighted how hard-wired, and thus quick to kick in and difficult to

273 overrun, the mechanisms of negative learning are:

274

275 We're not looking at it that often and, as always with the bio-feedback, when you're looking at it

276 and you're not getting anywhere, you think, "oh, I won't bother again then"! *[Palliative care professional 1]*

277 [I]t's a bit demoralising when you find the ambulance service won't look at it [templates]! ... [Y]ou

278 just think we've got better things to do, because if you have a rat and you want to motivate a rat to fill that in, you'd be giving the rat some praise while people are looking at this! *[Out of hours staff 3, GP]*

279

280 Similar Catch 22 challenges included: needing to see something in action so that you realise

281 its huge potential and benefits, while, on the other hand, people tend to engage with

282 something if they already see its benefits; and fast disengagement due to "clunky" and

283 potentially unsafe aspects of the process (e.g. using a "human" coordinator to upload

284 information from non-interoperable systems), while sustained or growing engagement is

285 necessary for the viability of the project in the longer term, when such limitations can be
286 improved upon.

287

288 The “emergent” nature of innovation also comes into tension with its equally important
289 dependence on a clear vision followed with determination and appropriate structures and
290 processes. Metaphorically, to get somewhere, we need to know where we are going. Yet it
291 is also true that some paths open only through the walking. The tension between those
292 equally valid positions could lead to conflict, particularly when team members had
293 contrasting working styles in terms of structure/ flexibility.

294

[E]very time we met, they would say, “Is our template there?” “Have you told us what template
295 you’re using?” “No.” “Have you had a project plan?” “No.” “Then what do you expect us to do?!”.
vs.

296

Every single project team meeting several things drop out and new ones come in and I don’t
297 necessarily see the logic as to why it had to be that way, other than that key players didn’t
necessarily bring the issues in fast enough, soon enough.

298

My contention is I could have spent ... an extra day a week into simply getting a nice spreadsheet
299 plan and changing the dates every single meeting. I could have done that. ... I’m not convinced it
would have changed the pace of the project.

300

301 Innovation is also developed to improve upon dramatically what is no longer good enough,
302 yet as long as something is “not broken”, it will remain good enough for a long time after a
303 new solution has become available:

304

I’m fairly stuck in what I was taught originally, for example the way that we write letters ... is
305 really a very antiquated way of doing it. ... However, it’s what I’ve used and what I always use,
and what my staff use here ... [I]t’s not broken, so we carry on with it.

306

[I]f we were unhappy really with the way in which we use our systems, we would call for help.

307

Cr But as it is, we’re not unhappy, because we’re used to it and you just carry on doing the work.

[both quotes GP 2]

308

as

money as well as the reorganisation of work processes. Yet overwhelmed clinicians and organisations simply cannot prioritise those vis-à-vis the needs of patients or their current targets:

[I]f you're going to learn something new, you've got to have time to do it and, quite rightly, they're focusing on seeing the patients who need to be seen and "this can wait, thank you very much."

So we've got the whole system [struggling] when, without much effort, they could start to look at the information, which will help to join up community and hospital, and create some efficiencies for them that they can actually meet their quality targets more readily ... [I]t was quite frustrating ... how difficult it is to get them to move.

Recent or current successes could also trigger a switch to autopilot, i.e. a disinvestment of funding and attention. For instance, the area where the EoLC data sharing project was being developed has long been amongst the national leads for end of life care, not least due to previous innovative work. Yet this meant that investment in it was a prime candidate for deprioritisation in the context of severe resources limitations:

[O]n the CCG level, the whole work stream around the End of Life care has run into the same problems in that there is no return on investment on any of these things. So it will all cost money rather than show any [left incomplete], because maybe nationally, as I understand it, we're not doing too badly on preferred place of death. So there's not a lot, necessarily, we can do to move a lot of activity out of [hospital], for example.

1.1.4. Uneven involvement ("In the deep waters – toes in the water – high and dry")

Even the most inclusive stakeholder group on a patient data sharing project cannot include representatives from all relevant settings and teams: over 330 was an inclusive, but not exhaustive, count of these for the EoLC data sharing project [53]. A project team is deeply involved with some settings and teams. It has on and off communication with others. Still

333 others are unwittingly excluded. In addition, representatives on a stakeholder group may
334 not be able to cascade information down successfully (e.g. if they do not have sufficient
335 power within their organisation) or may not escalate it up from the lower levels (e.g. if they
336 do not do sufficient frontline work or the staff-manager relationship is strained).

337

338 Unless a process is established to collect reliable feedback and data across the board,
339 distortions of perception arise. The enthusiastic engagement of and collaboration with some
340 settings can blur the complete lack of awareness and involvement on the part of others. The
341 managerial-level feedback may not represent accurately realities on the ground. Actions
342 agreed with on-off settings may not be taken forward while the team considers them
343 implemented or at least “work in progress”.

344

345 *Interviewee:* [T]here’s all this work done on these End of Life templates and there’s also the care of the
elderly templates, which, in 111, we’ve got access to those, we don’t have them in [organisation] yet.

346 *Interviewer:* Don’t they?!

Interviewee: They do not!

347 *Interviewer:* Interesting.

Interviewee: I keep muttering about this, it’s something that I think should change, but at the moment
348 they don’t have access to them.

Interviewer: I believe [name], who is on the team, believes that they do. But you ...

349 *Interviewee:* Well [pause], I work there.

350 It’s partly our problem if the team that are going haven’t fed it back, then it’s yeah, that’s not so much
351 your problem. If you’re giving them the information, then they need to pass it back to us.

352 *Interviewer:* I was going to ask if there was a team discussion whether you would like to join?

Interviewee: [Laughs] Not that I remember! ... We are using it because, as I said, we were really told we
353 would have to use it and that was that, there wasn’t a discussion. Which is fine, but without really
understanding what benefit it was going to give or how helpful it was going to be, so [left incomplete].

354

355

Supplementary file 2 (S2) offers quotes on the remaining challenges under the radical innovation category, which were less frequently mentioned:

1.1.5. Overvaluing the uniqueness of one's project or idea ("Lovely baby problem");

1.1.6. Securing a host/ sponsoring organisation ("Finding a home");

1.1.7. Impact of delayed external innovation, i.e. knock-on effects from delayed external projects, the outcomes of which were factored in one's own innovation ("Innovation domino");

1.1.8. Slipping timelines ("We are scheduled to finish 6 years ago").

1.2. Challenges of working in the health service ("Living on the Edge")

The challenges inherent in the very context of (UK) healthcare appeared to be the most prominent topic in the whole study, even if not data sharing specific and even if emerging without a specific prompt in the interview schedule. (Assertion about dominance is primarily based on the volume of quotes in a key quotes document. No systematic quantification was conducted, as this could not be a criterion for prioritising messages in a qualitative study.) We have, however, chosen to represent such issues only schematically, as they are well known and broadly discussed.

1.2.1. Resource limitations

Even if the tools of the EoLC data sharing project were free to all teams, settings and organisations, broader resource limitations had direct impact on the time and human resources they could dedicate to adopting them. The key resource limitations identified by interviewees were financial strain; staff shortages; high staff turnover in settings particularly relevant to end of life care, such as care homes; the disproportionate impact of staff

shortages on remote areas; the stretching of roles (e.g. roles “disappearing” when a person leaves, or working overtime and outside of one’s remit to cover for roles not recruited to); and the competition of priorities for attention, money and staff time.

More rarely, interviewees mentioned: insufficient equipment (e.g. syringe drivers); financial counterincentives that exacerbate staff shortages (e.g. much higher levels of insurance to work in out of hours services); the self-centred choices of some patients in a service free at the point of care; and saturation with certain aspects of one’s role (e.g. training delivered by enthusiastic clinicians when need far exceeded original intentions and comfortable capacity). Quotes below are on financial strain, prioritising, and some basic aspects of staff shortages; quotes on the other challenges can be found in S2.

None of our hospitals are truly viable, our [Trust 1] is not viable, but it might be rescued by taking on [Trust 2] staff, expanding. [Hospital 2], who knows what the future there is? [Hospital 6] is completely broke, it loses 25-30 million a year and it has a PFI [private finance initiative] that it’s short of another 25 million every year.

[E]nd of life is part of many problems for 111, one of many of the ambulance trust problems, so it might drown a little bit in the priorities.

I get really upset talking about this [pause].

[H]e’d actually fallen out of bed and she couldn’t get him back to bed, so when I came back from [city] that day on the Sunday afternoon, I went round to see him and he was dead and he was on the floor, because she couldn’t lift him and because the district nurses had said again that he wasn’t important enough.

[A]nd the reason for this was not because they are awful people who hate my patients, it’s because the community nursing service are based elsewhere and it takes half an hour to drive out here and see somebody, and then half an hour to drive back, whereas if they’re in [cities], it takes them 10 minutes to drive somewhere. [GP 2]

1.2.2. Fragmentation

The high level of fragmentation within an otherwise national system was another source of generic but, potentially, uniquely harmful challenges, as data sharing projects are by definition cross-organisational. This fragmentation arises from and feeds back into:

- significant levels of autonomy of organisations, and to some extent professions, within the UK health service;
- the lack of clear mechanisms for driving multi-setting projects;
- the multiplicity of simultaneously running and often overlapping projects;
- the lack of sufficient central/ national leadership.

Less frequently, fragmentation was discussed in terms of:

- mismatched targets of different organisations;
- health professionals lacking an overview of the patient journey and/or understanding of the role of their colleagues in it;
- the uncertain status of involvement in many cross-organisational projects (on the one hand, the involvement of an organisation may not be resourced from new funds, but is still expected on the grounds of “we are the NHS”);
- the fragmentation of not only patient facing services but also of local structures aiming to provide organisational support (such as IT support teams, local training initiatives or service development support, including in end of life care).

The impact on data sharing of the health service fragmentation was experienced even more acutely in geographical and administrative boundary areas, which were often moving backwards and forwards in their belonging to local healthcare structures. Also, services with a broad geographical coverage, such as the major referral hospital for the region, had large

428 numbers of patients not covered by the EoLC data sharing project, as such patients were
429 coming from “other” Clinical Commissioning Groups.

430

431 1.2.3. *Constant transformation*

432 The constant change, transformation and innovation in the health service also had direct
433 impact on the uptake of data sharing projects. It was “nothing personal” to a project but,
434 nonetheless, a major block to its uptake and viability. Apart from generic discussions of
435 constant change, the interviewees expressed frustration with projects coming and going;
436 pervasive project fatigue; new initiatives being experienced as taking health professionals
437 away from their patients or as yet more unresourced work.

438

One of the troubles the NHS has is that it never lets systems bed down, they always change before
439 they have done so, and because everything is changing, the message never gets down firmly to the
lower levels that are providing the patient service. *[Out of hours professional 3, GP]*

440

[S]ome GPs will be very aware that they’re so busy trying to meet targets that they’re no longer
441 caring for their patients, so they get very frustrated when new projects and new tools and things are
442 put in their place because they think “oh, another thing I’ve got to do that doesn’t allow me to sit
and look at my patients and make sure that they’re OK”.

443 There is template fatigue and there is Dashboard fatigue out there, but that is nothing particular to
444 the project, that’s just the way people are at the moment, and there’s a considerable amount of
initiative fatigue because there seems to be a new initiative every day in the emails that come out.

445

446 1.2.4. *Environment deprioritising “extras”*

447 Resource limitations, the pace of change, and, to some degree, the high levels of
448 fragmentation in the health service fused into an environment where data sharing projects
449 were almost understandably deprioritised in practice, even if there was in-principle
450 commitment to them. Features of that environment were:

- relentless, overwhelming pressures, affecting both the capacity and morale of staff and organisations;
- focus on “core business”;
- culture of responding, firefighting, urgency and short-termism rather than long-term thinking;
- crude decision-making models overdetermined by a concern for saving money, now;
- high levels of attrition and replacement of representatives from different organisations, with replacements often coming from lower hierarchical levels and not given the appropriate hand-over information.

[I]t’s very hard to be proactive when one’s overwhelmed. *[Palliative care professional 3]*

The system is grossly overloaded and because they are working harder and harder, they’re making more and more mistakes, which is becoming more and more costly and causes more admissions to make it right. *[Out of hours professional 3, GP]*

It’s very much, “Will this stop an inappropriate admission? Yes or no? Tomorrow?”.

[W]e can’t do long-term commissioning, we don’t see the results of what we put in place, we don’t allow a project to run enough or long enough to pick up and become embedded into the health economy before we have to evaluate whether it’s value for money.

And that means that we open and close, open and close quite a lot of projects, and that’s quite depressing.

1.3. Work in large impermanent teams (“Motley Crew”)

The third most frequently mentioned type of pure challenges arose from working in a large impermanent team, bound by a loose hierarchy and limited shared lines of reporting and accountability. In our framework constructed around issues broader than health IT, this type of challenge is shared, for instance, with work in international organisations such as the

United Nations or the World Health Organization. Participants in multi-setting data sharing projects have a key common goal. But they have multiple further goals around what data sharing should look like so that it benefits their organisations and staff as best as it can, also in the context of multiple other agendas their organisation is committed to. To clarify, work in large impermanent teams outside of standard hierarchical and accountability structures can have immense positives and run (relatively) smoothly. However, in our set of interviews, collaboration between settings and teams within the health service was seen overwhelmingly negatively.

Responsibility for this, with minor exceptions and careful phrasing, was *not* attributed to the data sharing project team and leadership. Interestingly, with minor exceptions again, the discussion remained at a highly specific level – as frustration with specific people or organisations rather than as something that might be driven by the structure everybody was working in. At a most fundamental level, issues included:

- “politics”;
- the importance of watching out for the interests of one’s own team and organisation;
- lack of action to match promises given;
- differences in language, including the embeddedness of each of the sectors involved in their own concepts and understanding (with the ones of IT, expectedly, a particular challenge):

499 Interviewee: It has not been a project is maybe what I will say.

Interviewer: ... And it has been what?

500 Interviewee: A game. ... Where tactics seem to be required. Of course it has been a project, I can't

501 really deny that, but finding ways of coordinating the diverse interests and using resources sensibly ...

[I]t's defeated me.

502 [T]hat's been discussed a lot during the course of the project ... the issues about time spent inputting

503 to a community system when we've got our own stuff to do. *[Palliative care professional 1]*

504 [I]t's got to work for us, it can't be that it's just a tool we've got to use. *[Palliative care professional 4]*

505 I've included their Chief Exec, I've got the Chief Exec involved. They've just got other things on their

506 mind. They say, "Yeah, it's a good idea and we'll make it happen", but they don't put weight behind it.

507 I don't know if people have got it in their heads that it's not a system ... I know that one of the team

508 members did attend a meeting where a colleague of mine had said, "You do understand this is not a

system?", to which they said, "It is a system". And it's slightly frustrating, because you think, "We've

had this conversation before!".

509

510 To complicate matters further, the messages of what were seen as distinct professional or

511 setting sectors were not as unified as expected:

512 [H]ow to get [IT experts] working in a totally entwined way and delivering a consistent

513 message, as if the two of them belonged in the same organisation and in the information and

systems and IT world, has defeated me.

514

515 Simmering conflict between stakeholders on the project, as well as limitations of

516 collaborative engagement, were seen as hard, frustrating and/or not managed too well,

517 particularly in early stages of the work.

518 There was a lot of conflict that needed to be managed early on, which I don't think anybody

519 handled particularly well and that has caused delays in the project.

520 I wanted to go and see [name] and her to run me through [clinical IT system] and three failed

promises, so I stopped there.

521 [I]t feels like they're pulling, that the acute trust side of things are pulling the strings and dictating

what they think they should have. And, ultimately, this is not necessarily about the acute hospitals.

522 Most stakeholders involved in the data sharing project belonged to external teams and
523 organisations (relative to the core project team). Their contribution was unpaid for by
524 project resources. This created precarious involvement arrangements, always with a
525 background risk that an individual or team disengaged. Concerns about disengagement also
526 limited the leads' capacity to manage or arbitrate in cases of conflict or performance falling
527 below expectations.

528 [W]e've got a whole load of NHS employees [on project team and stakeholder group] and we rely
529 on their contribution as a point of goodwill, all of them can, in essence, refuse to cooperate.

530 [I]t is not a good thing for me to be leaning on people and demanding of them to do it faster or
quicker or ... better, if what they'd done was not good enough ... [N]ot when it's not their main job.

531 [A]nd, in the end, I have to admit, I gave up and just thought, "well, let the project go on when it
532 goes on, that's, I'm not going to lose sleep over it, I'm not the project manager, I'm not
accountable for delivery of it". But ... it doesn't sit well with me.

533

534 Importantly, the project was started by a substantial innovation grant and was largely
535 independent, even if embedded in the local health economy. If it took its own direction
536 against the advice of some stakeholders, those stakeholders had little formal ways of raising
537 an objection.

538

539 [T]hat caused quite a bit of fallout because here we were [project team], telling someone in
[organisation] that we were not going to follow their advice and they were certainly not very
540 happy. So that did make life very, very difficult for a while.

541

542 Disengagement could be particularly hard to detect from individuals and organisations that
543 were inconsistently represented on the working group. In several interviews it became clear
544 that agreements for action in/by certain organisations reached at meetings (and not

enshrined in written documents) were not followed up on, with no update provided to the project team (see “Uneven involvement” above).

Outside of the direct work of the project team, but still with direct implications for the EoLC data sharing project uptake, some interviewees described situations of “passing on the buck” around infrastructural solutions, even when the costs were relatively minor.

[W]e need a little bit of infrastructure, probably costs 3,000 pounds or something for them [care home] to do that, and that’s peanuts, but that’s not happened yet. I’m still in firm negotiations to try and get them to pay for it, I’ve refused to pay for their internet access line. [GP 7]

1.4. IT work, narrowly construed (“We’ve known you for so long”)

The multiplicity of non-interoperable clinical IT systems and the complexity of Information Governance (IG) were the two leading challenges in the *IT work, narrowly construed* category, in terms of degree of attention given to them by interviewees. IG is not discussed here, as the level of detail around it demanded a separate paper.

Arguments around choice and allowing variety and competition to drive continuous improvement are uncontroversial in many contexts. Yet if a health professional commented on the variety of clinical IT systems, it was in terms of it being at best incomprehensible (“it’s just daft, isn’t it”; “makes no sense” [Out of hours professional 4, GP]; I just don’t know how that could have happened, but I’m sure there must be some vested interest” [GP 7]; “it’s a shame”; “just seems bizarre” [Out of hours professional 1, Nurse]).

A small number of interviewees also warned that technically enabled integration may not be meaningful practical integration. For instance, the movement from one “integrated” system to another could be unidirectional. The forwards-backwards switching between systems for recording/ checking of information was not necessarily possible without complex, and potentially unsafe, workarounds.

In addition to the multiplicity of systems and their lack of interoperability, several further and familiar aspects of a digital environment lacking maturity were discussed:

- unresolved challenges around mobile working;
- “stickiness” of old clinical IT systems and software more broadly;
- the lagging behind with the implementation of comprehensive IT solutions in key settings;
- the lack of even basic infrastructure in some settings (e.g. secure email in hospices or “dead zones” for internet in care homes);
- the presence of pockets across the health service where paper notes were still the norm;
- generic signal issues.

Inadequate users’ knowledge and skills were also mentioned, including:

- generic IT skills, particularly in some staff groups;
- limited understanding of record sharing;
- the impossibility of convening a project team where all members had high level IT skills in addition to their primary expertise (e.g. in end of life care or project management).

Rarely, it was pointed out that IT systems are, after all, “work in progress”. Even the best amongst them may not necessarily live up to their promise; may not be improved upon fast enough; and ultimately fail for the needs for which they were sought, developed or bought, often after significant financial investment.

Detailed quotes on this category are only represented in S2, as the issues are amongst the most broadly discussed in health IT and patient data sharing.

1.5. Rules, laws and algorithms in spaces also calling for humanity, flexibility and art (“How to Repair a Broken Human. A Manual for IT Systems”)

In discussing data sharing and health IT more broadly, several interviewees touched on their “orderly nature” – of rules, algorithms, logic, rationality, 1s and 0s, clear boundaries, etc. – and the ways in which it does not match the nature of health care. The latter was anything but orderly – exceptionally complex in its organisation, pathways and decision making professes (even irrationally complex, particularly in the historical organisation of services); dealing with suffering, embodied humans whose pain, needs and behaviours cannot be easily slotted into templates; and often requiring as much art and creativity as it requires science and logic. This tension is familiar from many other domains (e.g. law, bureaucracy, governance, traditional project management when applied to “messier” areas of life) and resonates with classic dichotomies of reason and emotion, science and art, machines and humans, objectivity and subjectivity, etc. Interviewees were variably cautious not to pitch those “worlds” and “perspectives” against one another or unequivocal about their personal allegiances and concerns:

616 [I]t's been challenging for the IT guys to understand the nursing perspective and the nurses to
617 understand the IT guys' perspective because they're just opposite types of people and that's a huge
generalisation, isn't it, but ...

618 And he rang me within a few days and said, "My life is transformed, I can't believe it, I'll be able to
619 go to my daughter's wedding, I'll be able to do all these things!". And you think, "Gosh, to be able to
make that happen at such an important time of life!".

620 So it's hugely rewarding, just those sorts of things would happen when you've been having a
621 particularly awful morning with either computers or paperwork or management or something, you'd
suddenly get a phone call like that and you just think, "Wow". *[Palliative care professional 5]*

622

623 Even health professionals who were self-professed "techie" and loved "fiddling" with
624 computers and new software, expressed significant frustration with some of the set-up
625 around data sharing, with windows and reminders unsynchronised with the flow of a
626 normal clinical encounter. Some were proactive to engage with developers in looking for
627 resolutions to challenges, but a positive outcome was not a given.

628

629 [E]very time you open up the patient's record you get a screen saying, "do this" [consider data
sharing]. It comes up before you can access the records, you have to click past it to access the record,
630 so, unfortunately, we go to see who's coming in, click it, it comes up, we then call them through and
it's gone when you need it. *[GP 7]*

631 Our call handlers have to tick buttons and say things like, "No clinician available", when in fact there
632 is one, "Put into queue", when in fact they're not going to be put into queue. Those calls are only
going to be warm transferred, and so they're having to click buttons that say the exact opposite of
633 what they're doing. It's a way of forcing the software to do something that it's not designed to do.

634 I do have a workaround for it, and I'm working on it, I haven't got it fully solved yet. We took that
workaround back to [provider] and they told us we weren't to use it.

635

636 At other times it was more debatable whether the clinical IT system was not "smart"
637 enough in mimicking actual working processes or whether those working processes had a
638 level of complexity that could be streamlined, with attempts to embed them in a health IT
639 tool serving to highlight them:

[T]he discharge letter goes to the GP which tells them what drugs they've been sent home with, including the just-in-case prescription. Then if it is a patient who we expect will need to use their just-in-case medicines from that day on, we will personally refer to the district nurses, but if it's more of an anticipatory prescription, we will then refer onto the community Macmillan team. Then at the time when it becomes necessary for them to use just-in-cases, they will get the district nursing team involved or the district nursing team would somehow get some more because the GP has contacted them. *[Palliative care professional 6]*

The remaining (sources of) of families of pure challenges we formulated were given secondary attention in the interviews. We present them below with brief descriptions and minimal quotes.

1.6. Core tasks – peripheral tasks (“Mixed Abilities Class dominated by a No Abilities Group”)

While end of life care is, in theory, a consideration for every patient and the palliative and end of life care community often upholds that “end of life care is everybody's business” [54], for many health professionals it is peripheral to their day job, as acknowledged in several interviews. When numbers of end of life care patients are relatively small for a healthcare professional and the domain is not a personal area of interest, defaulting to referring patients rather than upskilling oneself may not be an irrational decision. From such a perspective, the data sharing project was akin to initiatives directed at both experts/specialists and non-experts (generalists, other types of specialists, and even the so-called “low-skilled” workers) where specialists are expected to lead the way, but are too few, and where the non-specialists are numerous, with various levels of pre-existing knowledge, learning needs, ability to shape their role by themselves, and motivation to become engaged in professional development that may not be crucial to their role. This

was, in fact, a challenge for the project from two directions – both end of life care and data sharing.

We know in our hearts that there's a lot of GP's that don't really care about End of Life Care. It doesn't float their boat.

Because I'm not in mainstream general practice now, I don't know what the understanding of it [data sharing] is out there ... [P]art of the problem was poor GPs have got so much to get their heads around that they're probably not bothered, and if they're sitting in their own little world, it doesn't bother them too much.

1.7. Work with highly sensitive, emotive, incendiary issues ("The Daily Mail")

In a similar way, the project was a double exemplar of work which carries the risks of touching on highly sensitive, emotive, incendiary issues: death and dying on the one hand and personal space, privacy and confidentiality on the other. Both issues were, indeed, in the centre of UK media storms as the EoLC data sharing solution was being developed and implemented – through the Liverpool Care Pathway scandal in palliative and end of life care and the *care.data* scandal in data sharing.

Although the tendency was to turn attention to how the media handles highly sensitive, emotionally charged issues, associated challenges were inherent to the project with or without media attention. Respectively, the knowledge and skills needed for successful, in-depth implementation were complex and time-consuming to learn.

[End of life care] is so emotive and people have all sorts of personal reasons for not wanting to engage with that.

[It's] complex and subtle and even tiny differences in how you phrase something – like, for example, in the DNACPR teaching we've just been doing, where we were talking about whether one says, "futile" or "no reasonable chance" or "only a very small chance" – all of these result in entirely different outcomes and responses from people ... [I]t's an art, these conversations, not an exact science.

1.8. Technology – human users (“Humans vs. Machines”)

A less discussed but well-defined source of challenges concerned the interaction between technology and users, with the former, no matter how automated, doing nothing fully by itself. The challenge was particularly prominent with regard to the quality of clinical record keeping and especially its underpinning coding. Issues around the unsystematic ways in which most of us learn to use technology also emerged.

[I]f you go for the last three entries, say, you phoned them up and couldn't get through to them and you write, “unable to get through on the phone”, and then one of the dispensers says, “message sent to doctor to check review date” ... you can end up with loads of “administrative offal” basically, which has no real clinical narrative in it ... and that blocks it up. [GP 7]

[L]oads of people are generating data but we don't have the discipline, and we don't have the systems, and we don't have the culture which sees it as necessary to be strict enough at the point of entry to actually generate stuff which makes a difference further down the track.

Interviewee 1: I've had not any update in my training in [System D] ever since I started, and you get the updates and changes, but who reads them?!

Interviewee 2: Me.

Interviewee 1: You are a geek! ... I rely on people like to tell me then basically [laughter].

[Interviewee 1 – Out of hours professional 1, Nurse]

1.9. Market forces in public services (“The Value(s) of Money”)

Finally, challenges around the presence of market forces in the health service were briefly noted. These were not specific to the EoLC data sharing project, but had an impact on it too. They came both from the direction of “too much” and “too little”:

[T]hey'd rather have a consultancy company coming in for three months, doing its bish, bash, bosh, this is how we're going to cut three million, five million, 10 million, 30 million off your budget and you all have to do that. And then three months later, they've left, they're gone and we have to pick up the pieces and then start again!

I just really struggle with the thought that [supermarket chain] can tell me how often I buy bananas, yet we can't work out a way of holding information to make somebody's end of life care better.

The EoLC data sharing project was non-commercial; funded by a research and innovation grant; and developed as a collaboration between the local health economy and a university, although also involving private sector contractors. Resistance against the presence of commercial interests in patient data sharing still affected the project though, as a generalised effect of a scandal around a national data sharing scheme (*care.data*; see 1.7 above). Curiously, in the whole study, no other name of an organisation or person external to the project was mentioned as frequently as the name of a UK supermarket chain – both as an example of efficiency in collecting and using consumer data and as “a face” for the fear of data sharing.

S 3 summarises the pure challenges described above and offers suggestions on addressing them.

2. PURE DRIVERS

We call “pure drivers” those drivers which, in our interviews, were not invalidated by claims of opposing challenges or this was occurring only minimally. The 4-component framework of pure drivers we propose is defined in terms of whether the driver is internal or external to the data sharing solution and the team developing and implementing it. The degree of internality/ externality is associated with a greater or lesser control of the project team over a driver as well as greater or lesser importance of the quality of the IT solution in itself.

Many of the pure drivers we identified already dominate the health IT discourse, particularly those related to: the (ideal) vision for patient data sharing; the features of a successful IT product; the characteristics of a good team, its leadership and allies; and the importance of

capturing the Zeitgeist. We discuss such factors only briefly, by way of reconfirming their validity in the context of end of life care data sharing and through a varied sample of interviewees, with the majority of quotes only presented in S2.

2.1. Pure drivers internal to the IT solution

Of the types of factors which propelled end of life care data sharing forwards and which were internal to the IT solution itself, the interviews highlighted:

- the ideal vision for the solution and its expected benefits (“Promise me the stars”);
- the quality of the solution in terms of functionalities, performance and user friendliness (“Easy like a Sunday morning”);
- the nature of the clinical domain (“Billion people/ billion dollar problem?”).

Of these, the vision for and expected benefits of data sharing were by far most frequently addressed. Amongst themselves, the interviewees identified almost 60 major and minor advantages of the broad sharing of patient data. Major perceived advantages were:

- avoidance of unnecessary and unwanted hospital admissions;
- improved medication decisions and increased confidence in making them;
- reduction of errors and improved patient safety;
- benefits to coordination and communication in broad multidisciplinary teams;
- difficult conversations at the end of life handled more sensitively, without shock or repetition;
- duplication of work reduced;
- resources used more efficiently and processes made more reliable and smoother.

The brevity of the core EoLC data sharing template as well as its simplicity, intuitiveness and good structure, which made it easy to use, were repeatedly highlighted by interviewees:

“it’s short and it’s concise and for clinicians, it needs to be quick”; “[I]t’s logically laid out, it’s

762 *quite intuitive ... and it's not too texty"; "It's quite straightforward". They obscured all other*
763 *functionalities, features and performance parameters of the data sharing solution.*

764

765 Importantly, the nature of the thematic domain – palliative and end of life care – was seen
766 as facilitating high level of commitment to data sharing:

767 [End of Life Care is] slightly different from everything else where we're looking at access rights to
768 a patient record, in that people just want joined-up care, so it doesn't get messed up when you
only get one chance right at the end. [GP 7]

769

770 **2.2. Pure drivers internal to the project development and implementation team**

771 **("Dream team")**

772 The personality and leadership style of the project clinical lead, the composition of the core
773 team, and the working style of its members as individuals and as a group were, with minor
774 grievances, evaluated highly positively by both team members and external collaborators.

775 The clinical lead of the project was perceived as engaged, approachable and visible; positive,
776 likeable and having personal integrity; with credibility amongst and strong connections with
777 clinical colleagues due to his specialist knowledge of end of life care, GP background, out-of-
778 hours services experience, and formal EoLC role in the locality. He was described as having a
779 clear vision for the data sharing work; inclusive of others and validating their contribution;
780 seeking to play to the strengths of team members and collaborators and to make them feel
781 valued; open to feedback and willing to listen; ready to deal with the "thorny issues" arising.

782

783 The core project team was considered to be representing a good variety of professional
784 backgrounds and organisational roles, with members being of high calibre in terms of their
785 knowledge, skills and expertise and also having sound understanding of local structures.

Some of the team members also had poignant personal experiences of end of life care, adding a further dimension of commitment and motivation. The working style of the team as a whole and of its individual members was described as “positive”, “motivated”, “willing to go the extra mile”, “solutions-focused”, “persistent”, even driven by a “dogged determination”. Colleagues were seen as “gracious” in being able to see “the bigger picture” when their preferences and recommendations were not followed, rather than treating the work as their “vanity project”. In critical moments, the team could stand their ground even against strong external influences.

This rather positive overall picture did not mean that conflict and tensions were not present, although they were greater in early stages of the project and also appeared disproportionately more often in expanded formats of the team when, for periods of time, external colleagues were involved intensely to advance the project in specific ways or settings. Such challenges were partly discussed under “pure challenges” above (*Large impermanent teams/ Motley Crew* section) and are attended to again under “ambivalent forces” below.

2.3. Pure drivers at the interface between the internal and external (“Invisible threads”, or “weaving a spider’s web”)

Significant work was required by team members to make the project fit with a range of features and requirements of the external environment, including:

- a national information standard for data sharing in End of Life Care;
- national and regional service monitoring and reporting requirements;
- local work on standardising data sharing;

- the local information management strategy;
- local incentive structures (e.g. through adding fields to the template that would make its use the easiest way to implement a positive process and also report on it).

Such work gave credibility to the project. It also aided its pragmatic attractiveness by allowing the simultaneous achievement of numerous goals if its tools were taken up.

Apart from the IT solution, the team or individual members also needed to “fit with” key structures in the external environment. Team members brought in pre-existing networks and connections or the “go-between”, “boundary-spanning” nature of their role as resources to the project. They also did new work to link with and influence external structures capable of advancing or slowing down the project.

2.4. Pure drivers external to the IT solution and team, but internal to the broader health IT ecosystem (“Catching a wave”)

In a small number of cases, interviewees mentioned developments external to the IT solution and work of the core team but happening within the broader health IT ecosystem, with such developments either already facilitating or potentially able to facilitate the project’s progress. These included the development of new functionalities by the providers of the main clinical IT systems; the trailblazing work of other data sharing projects; the thoughtful practices of individual organisations and health professionals around consenting patients to data sharing in general, prior to and independently of this project. Most importantly, such a pure driver was the “crest of the wave” of interest in data sharing across the health economy, which had grown exponentially since the beginning of the project. This

included some highly positive attitudes on behalf of health professionals and patients.

Quotes on all types of pure drivers can be found in S2.

3. OPPOSITIONAL AND/OR AMBIVALENT FORCES

If we were to exclude quotes on either Information Governance or generic health service

challenges from the category of “pure challenges”, most of the interview contents would

belong to the third broad category of parameters, “oppositional or ambivalent forces”.

Expectedly, some interviewees saw an issue from the perspective of the problem, while

others saw it from the perspective of a (hoped-for) solution, in the familiar manner of a cup

being half-empty or half-full depending on the observer’s mindset. This could also be the

case with one and the same interviewee at different moments in the conversation. For

instance, if the challenge was lack of knowledge and skills in palliative and end of life care,

its counteracting driver would be providing training. This relationship of resolving a

challenge through a naturally matched driver characterises what we call here *oppositional*

forces.

More typically and less expectedly though, some interviewees saw a factor as driving

something positive in data sharing and patient care while others perceived it as a challenge

to achieving something else – still highly valued and still pertaining to patient care, often

even to data sharing. This relationship defines one subtype within the category of

“ambivalent forces”. In the remainder of the Results section, we summarise the discussion

on oppositional and ambivalent forces and clarify the concepts further.

3.1. Oppositional forces, temporary (“The race is on”)

With “oppositional forces”, challenges and drivers appeared as a negation of one another.

Typically, the driver was a head-on attempt to resolve a challenge. In the case of *temporary*

oppositional forces, the driver resolved or would resolve a problem. The solutions appeared:

- at the *interface* between the internal and external (most frequently discussed), such as the timing of a project launch within a new organisation so as to avoid major internal upheavals (as was the case of introducing an electronic patient record in one of the hospitals); good preparation for the initial hard work of implementation and the associated “resistance and tears”; or integrating the educational intervention of the project with another local educational intervention in end of life care.
- *External* solutions could also be vital for the project uptake (e.g. the challenge of additional and multiple log-in processes, passwords and user profiles was envisaged as resolved, in the future, by a single log-in solution.
- *Internal* solutions were not easily discernible, potentially because their implementation would be day-to-day business for the team, rendering them too routine to be visible.

3.2. Oppositional forces, reoccurring (“The eternal battle of good and evil”)

In most cases, however, the challenge could not be resolved once and for all with a single,

be it complex, action or programme. Rather, certain tasks needed to be integrated into

routine services or effort to be renewed at regular intervals. The tasks of a data sharing

project thus bore resemblance to chores like house cleaning or painting, or to goals such as

maintaining a healthy weight. Most prominent examples of such dyads of challenges and

drivers were:

- the lack of knowledge, skills and awareness, whether in end of life care or data sharing, vs. the provision of appropriate training initiatives;
- the lack of information and/or the presence of negative communication patterns vs. the reliable provision of information and the engagement in good, effective communication;
- acting from the “wrong motives” (such as hitting organisational targets, meeting the requirements for additional financial incentives, or focusing “on what keeps the Board in a job”) vs. acting in view of the patients’ needs and interests.

Interestingly, interviewees discussed such problems and solutions in the abstract, with only a few making a comment of their recurring nature. Even when the recurrence of the need was mentioned, it was primarily as something frustrating and inconvenient or as a problem confined to particular settings, e.g. care homes, where staff turnover was high, rather than as a largely generalisable feature of certain types of work.

Finally, there were challenges where the matching driver was clear, but perceived as largely in the realms of “wishful thinking”, such as having more district or specialist nurses.

3.3. Ambivalent forces: legitimate differences in clinical or paraclinical context (“All in the open or skeletons in the cupboard”)

A very small number of interviewees (conceivably, because this was an “obvious” consideration) highlighted how different patient conditions would necessitate different choices with regard to data sharing. This concerned primarily circumstances where a patient’s record contained information about, for instance, sexual health, mental illness,

906 sexual abuse, domestic violence, criminal convictions as well as conditions which limit
907 access to certain professions or compromise rights to insurance claims. Such cases could, in
908 principle, be identified and circumscribed for special data sharing arrangements. Yet the
909 selective withholding of information from the whole of a patient's record was reported to
910 be unfamiliar or difficult and to create challenges of its own.

911

912 In a further set of clinical contexts (though less pertinent to end of life care), data sharing
913 could be largely irrelevant, e.g. in cases of seasonal illnesses or bone fractures of young
914 persons. The presenting acute situation (over-)determined the course of action, leaving little
915 room for hesitation and the associated need to seek clarifying information.

916

917 Circumstances of extended hospital stay could also limit the value of accessing information
918 from community services or sharing it back with them.

919

920 Most consequentially, there are irreducible differences between the record keeping needs
921 of a health professional who generates information for their and their organisation's own
922 needs and the informational needs of other potential users. Information which enables
923 one's own work can be irrelevant, too much or too little for those receiving it. To address
924 this challenge, specialist palliative care teams, for instance, were completing two templates
925 – one for sharing and one for their internal needs, with the cross-population of information
926 enabled in one but not in the other specialist setting. The mismatch of needs became even
927 more significant if the recipients were the patients themselves (one aspect of what we have
928 here termed "paraclinical context"). While some solutions could bridge the gap, it would
929 always remain a question of "squaring a circle", i.e. without an ultimate resolution.

(See “expected benefits” for the contrasting type of contexts, where data sharing is crucial to providing high quality care. Note that the total number of expected benefits was almost 60 and necessitated the inclusion of the category under “pure drivers”. Only a minimal subset of these drives had a parallel in the challenges discussed here, making them “ambivalent forces”).

3.4. Ambivalent forces, divergence of values or complex entanglements (“One man’s meat – another man’s poison”; “You don’t find roses growin’ on stalks of clover”)

One of the richest subtypes of “ambivalent forces” had its roots in differences, at times radical, of perspective, values, mindset, sets of needs and goals, etc. relative to which a factor was considered. Such a diversity was understandable and legitimate. Yet the clash of opinions that could result from it bore similarities with political or paradigm “wars” in terms of the intensity of attachment and the difficulty of finding a satisfactory meeting point.

In some cases, the diversity of values, mindsets, perspectives, etc. had a direct impact on specific features of the data sharing solution and even on the foundations for its existence.

These features/ foundations included:

- *the nature of “the template”*, shaped by bridging the diversity of opinions on whether it should be more comprehensive vs. more concise; multifunctional vs. having a clear scope; more structured vs. more text-based;
- *the foundations for the very possibility for data sharing*, depending on whether organisations would see more benefits in keeping their in-house templates, far better tailored to their own needs, or converting to templates standardised for use

across the local health economy and enabling better (or even any) data sharing – a choice often driven by an overarching preference for greater independence vs. greater collaboration;

- the *particular type of data sharing advanced*, with different opinions expressed whether having a template and a view, overlaid onto the more generic sharing of a patient's record, is of sufficient added value; whether planning future care and consulting existing care plans has sufficient advantages over the immediate, adaptive response to what is, essentially, always a new clinical situation; or whether certain types or professionals should be having editing rights or not.

Each of the above extremes could advance some opportunities and goals (act as a driver) and constrain or block others (act as a challenge). No interviewee argued for any of the extremes, such as a tick-box only or a text-only template. Not infrequently, they acknowledged some advantages of the alternative perspective or described their own trajectory from practising differently (such as using an in-house template) to their current preference (endorsing a locality template to enable data sharing). But with the exception of one interviewee, who discussed pros and cons in a rather equitable manner and did not commit to a personal conclusion, all had clear current preferences for one or the other side on the above continua.

978 [T]he view is just incomplete. [*Out of hours professional 4, GP*]
 vs.
 979 I believe in very precise concise information ... [S]ome of these templates are too long and we
 don't need all of that information, most of this is repetition. [*GP 5*]
 980
 981 I am very concerned. A lot of GPs are very concerned about where the NHS is heading.
 Obviously, we're very fiercely independent, that's why we are like we are. [*GP 1*]
 vs.
 982 That kind of loss of control of data is something GPs do have to accept, that we can't, there's
 no way we can work individually, and I'm very happy to relinquish control to other groups or
 983 clinical teams. [*GP 7*]
 984
 985 The differences of perspective could also concern more diffuse characteristics of the data
 986 sharing project, such as *its progress and success* or the *support structures* in which it was
 987 embedded or which it had set up (e.g. the composition and effectiveness of the broad
 988 stakeholder group; the work done by the pilot site; the overall value of the training aspect
 989 of the project; the adequacy and fairness in distributing project resources; the value of an
 990 external role negotiated to provide support, etc.).
 991
 992 We're in a fortunate position that the budget is incredibly generous.
 vs.
 993 [W]e'd factored in some monies to support having a dedicated resource or dedicated time to be
 able to deliver this, however, on the re-evaluation ... there wasn't any resource identified ... [so]
 994 we had to try and add this onto our existing workload, it wasn't a planned full project in effect.
 995
 996 I can't see it [end of life care data sharing] surviving in general practice without co-ordination.
 Having the MDT co-ordinators was a really big change, it really enabled things. [*Palliative care*
 997 *professional 5*]
 vs.
 998 [N]obody's really sure what they're supposed to be doing. I've got an idea of what I want our MDT
 coordinator to do, but I'm not sure whether my idea will fit with her idea of what the job is.
 999
 1000 A particularly interesting category of "ambivalent forces, complex entanglements"
 1001 concerned the (positive) self-awareness of some key informants about negative aspects of
 their work. This could be about actions that have generated "antibodies" in collaborators or

1002 about people struggling with their role but doing their best to “keep their head above
1003 water”. To an extent, such self-reflective comments aimed for a narrative resolution of
1004 something that might have required practical solutions.

[T]hey’ll regard me as bossy boots and a heavy weight in more than one way. ... So it was just probably the, it was my fault for the way I tried to explain it.

And maybe the project manager should have been someone like [name] who might, with a grasp of the detail around [System D] requirements and information governance and things like that ... the theory of how to manage a project would have been better followed.

I envisaged initially that I would do this up to a point, until somebody else came along ... and I could hand over the reins, but nobody’s appeared and I don’t know whether that’s because I’ve ... kept my head above water.

1005

1006 **3.5. Ambivalent forces, unintended consequences (“Dark side of the moon”)**

1007 In a key pattern of a driver-challenge relationship, overall highly positive outcomes of data
1008 sharing could have powerful unintended consequences, including:

- 1009 ○ The greater ease with which GPs could obtain specialist (palliative care or other)
1010 advice, by having specialists access the GP record, could mean that more GPs felt
1011 their work was interfered with or their judgement questioned.
- 1012 ○ The provision of more informational support to clinicians who were uncertain in
1013 their judgement could mean that they experienced greater pressure to make
1014 decisions they felt uncomfortable with. Alternatively, they might become
1015 unjustifiably confident in their ability to make decisions requiring expert input.
- 1016 ○ Informing colleagues, through a shared record, that one has initiated an aspect of
1017 care (e.g. conversations around the end of life) could result in the other side taking
1018 such aspects of care as handled with as opposed to initiated.

- 1019   ○ Being able to see a well established clinical history could prevent the fresh
1020   perspective which would have provided the solution.
- 1021   ○ Crucially, having up-to-date external information could be highly valuable, but
1022   having outdated information, which could be the case even if the record appeared
1023   up-to-date (e.g. because services unrepresented on the record were involved along
1024   the way), could be far more dangerous than acting from the situation at hand.

1025   Whether it was a patient, family or a specialist nurse or even a district nurse ringing up and
1026   saying, "It's all going wrong", you could look on [System D] and see what was happening ... and
1027   sometimes GPs were not very pleased with us for interfering. [*Palliative care professional 5*]

1027   [The GP can think], "this has been done, so I don't need to do anything now, I'll think about it in
1028   a month or whatever". [*Palliative care professional 1*]

1029   But then just by nature, just by how human nature [is], that's how we sometimes think, aren't
1030   we, we look back and think, "Oh, you've already phoned up about this or you've already had
1031   lots of problems", and ... that might change your opinion or change your thoughts about a
1032   certain patient, rightly or wrongly. [*Out of hours professional 5, Nurse*]

1032   Less frequently identified types of ambivalent forces included:

1033   3.6. "*Inequality considerations*" ("*Princes and paupers*");

1034   3.7. "*Reversals of the negative*" ("*From effect to effect*", "*Rainbow after the rain*");

1035   3.8. "*Conflicting or unclear evidence*" ("*Unknown quantities*");

1036   3.9. "*Vicarious learning or feeding on the failures of others*" ("*Digital sages or digital
1037   vampires*").

1038

1039   Schematically, these factors and proposals for actions to address them are presented in S3.

1040   Quotes are given in S2.

1041

1042

1043 **DISCUSSION**

1044 **Summary of main findings**

1045 Here we presented a comprehensive yet parsimonious framework of challenges, drivers and
1046 ambivalent forces to patient data sharing, with a focus on data sharing at the end of life.
1047 The framework was derived from a rich dataset, consisting of in-depth interviews with 45
1048 maximum variation participants, many of whom were “key informants”. Findings from the
1049 interviews were also mapped against findings from four literature reviews on health
1050 information technology and health information exchange, covering 135 studies (the
1051 inclusion of one and the same study across reviews was explored and the number of unique
1052 studies is likely to be lower; yet a level of originality of interpretation is expected to
1053 characterise each review.) The framework we are proposing was also developed through a
1054 highly iterative analysis process. It involved seven stages of coding and/or mapping the data,
1055 each of them comprising multiple iterations. Our final proposal is for a 9-component
1056 framework of “pure challenges”, drawing parallels between patient data sharing and other
1057 broad, complex and, historically, far more long-lived domains outside of health IT; a 4-
1058 component framework of “pure drivers”, defined in terms of their internality or externality
1059 to the IT solution and project team; and a 9-component framework of “oppositional or
1060 ambivalent forces”.

1061

1062 We have also offered (as supplementary material) proposals for practical actions based on
1063 or informed by the data, also building on findings from other arms of the broader study
1064 [53,55-58], the broader research and IT literature, and our participation in the applied
1065 aspect of the project. These are well grounded proposals but nonetheless requiring further
1066 refinement, testing and evaluation.

1067   **Implications for practice**

1068   A significant level of complexity eludes us when we abide by a loose understanding of
1069   challenges as “negative factors” and drivers as “positive factors” that also stand in simple
1070   opposition to one another. Challenges and drivers form a broad range of relationship
1071   patterns. The frequency with which complex factors can function, or appear, as both
1072   challenges and drivers highlights the vital importance for a data sharing project of skills in
1073   eliciting the assumptions of stakeholders; in managing conflict; facilitating good decision
1074   making processes; and navigating multiple needs, interests and even “worldviews”, amongst
1075   others. It can be argued that “bridge-building” skills and “go-between” roles will often
1076   advance a data sharing project far more than high level IT skills and domain-specific clinical
1077   and procedural knowledge.

1078
1079   It is also important to acknowledge that certain tensions between “a driver perspective” and
1080   “a challenge perspective” towards the same issue will never be resolved. There will always
1081   be situations when that which advances one valued goal simultaneously blocks another
1082   valued goal. Perhaps most notably in this respect, informational needs may differ
1083   significantly across types of health professionals and contexts. It is often sorely inadequate
1084   to “just share” the data. Instead, they may need to be selected, reorganised, rethought,
1085   condensed, expanded or otherwise manipulated.

1086
1087   Similarly, while data sharing can produce profound positive outcomes, it can also lead to
1088   unintended consequences which are inseparable, or at least inseparable without much
1089   further work, from the positive consequences it generates.

1090

1091 More positively, organising the “pure challenges” around features and tensions familiar
1092 from other types of human endeavour brought to the fore a wide range of related project
1093 types from the arrival of the railways, through working with dangerous equipment, to
1094 teaching mixed abilities classes from which health IT work, and data sharing work more
1095 specifically, can draw lessons and inspiration. The IT world is, indeed, unique and new
1096 (though, arguably, no longer *that* new) but it is still more akin to other forms of human
1097 endeavour than we may be acknowledging at times.

1098

1099 This articulation of similarities with other major fields of work also helped demonstrate why
1100 data sharing projects can be so notoriously complex and often disappointing in their
1101 progress and outcomes, as much as the core logic underpinning them seems unshakeable.
1102 We are not simply dealing with an intersection of the (complex) IT world and the (complex)
1103 healthcare world. We have at least nine “complex worlds” coming together in a tight knot of
1104 interactions we cannot fully trace and unravel. With some types of projects, and Electronic
1105 Palliative Care Coordination Systems are a case in point, some of those nine threads are of a
1106 double strength, e.g. because both end of life care and data sharing can become highly
1107 emotionally charged issues or because the “mixed abilities” in terms of knowledge and skills
1108 can, again, concern both the IT and the clinical domain skills.

1109

1110 In terms of the future of the Electronic Palliative Care Coordination Systems (EPaCCS) in
1111 England, of which the project under consideration was a leading example, we consider the
1112 findings of the current study as suggesting that EPaCCS may need to be gradually phased
1113 out and integrated into more comprehensive data sharing solutions. The level of challenges
1114 EPaCCS are facing may not be within their capacity – or within the capacity of any single-

1115 condition project – to surmount. It may be wiser if they move towards merging, sooner
1116 rather than later, with the Local Health and Care Records [59] or other more encompassing
1117 solutions such as broader urgent and emergency care records. Even if EPaCCS are phased
1118 out, this will not be effort and money gone to waste unless we allow it to. Since 2008,
1119 EPaCCS teams have been working on types of challenges that Local Health and Care Records
1120 teams have started to address much more recently. Reconfiguring EPaCCS in a way that
1121 subsumes them within broader data sharing solutions may be an occasion when less is
1122 more.

1123

1124 In terms of the drivers we identified, the pattern of organising them here indicated an
1125 interesting and, at first glance, counter-intuitive “fitting in” recommendation in an
1126 environment where “standing out” is considered a product’s most important asset. Yet a
1127 health IT project needs to be responsive to numerous standards, structures and processes in
1128 the health service, in addition to their IT-specific counterparts. A big part of the work of a
1129 development and implementation team is thus to ensure that their product fits in, that it
1130 ties in with as many processes and external structures as possible. Typically, developers
1131 focus on perfecting their IT solution and/or “hustling” to sell the vision for it while some far
1132 more socially oriented, quieter and less glamorous work could, perhaps, lead them to
1133 greater success.

1134

1135 More broadly, the whole study underscored the importance for developers to look outside
1136 of the IT tools they are building and refining. Over three-thirds of the drivers and challenges
1137 we identified at the level of the 800-component intermediary framework did not pertain to
1138 the IT solution at all.

1139   **Implications for research**

1140   Apart from being exceptionally difficult to design and implement, patient data sharing
1141   projects are also a hard “research nut” to crack. They are a challenge for which conventional
1142   health services research is ill prepared. Data sharing projects are, by definition, multi-setting
1143   interventions. This creates significant difficulties of access to data and participants. We have
1144   described some of the difficulties pertaining to the research approvals for the current study
1145   elsewhere [58]. Yet even needing 89 individuals to sign off a research study, as was the case,
1146   is a light-touch task compared to the task of setting up a rigorous study design to evaluate
1147   the outcomes of introducing an EPaCCS. As mentioned above, there were at least 330
1148   settings or teams, in an inclusive but not exhaustive list, that could be served by the tools of
1149   the Cambridgeshire & Peterborough EPaCCS. EPaCCS are complex interventions in an
1150   exceptionally complex context. They are also work in progress. The research object at the
1151   start of a study has little in common with the research object at the end of the study, and
1152   this is only partly related to the deepening of knowledge that happens in research. It is a
1153   genuine transformation of the object of study in the process of it being studied.

1154

1155   Very importantly, data sharing projects – and in this respect they are typical innovation
1156   projects – are in urgent need of positive evidence in order to ensure their viability and
1157   future funding. No responsible research can aim to “provide evidence for the effectiveness
1158   of an innovation”, yet this would often be the reason a research and evaluation component
1159   is added to a data sharing project. We need to protect the integrity of research and
1160   evaluations on data sharing, but we also need to create a meaningful buffer of opportunities
1161   for data sharing projects to progress without compelling evidence in their favour. Much
1162   innovation, perhaps most innovation, is not accompanied by evidence of impact that is both

1163 impressive and rigorous in its early stages. Innovation is innovation because it is
1164 underdeveloped, emergent, work in progress. Many things will go wrong before an
1165 innovation team and the networks of actors associated with it find the right path to follow
1166 and begin to see the pieces coming together both as intended and as nothing like it. The
1167 most interesting innovations are also complex interventions in exceptionally complex
1168 environments. It takes time for researchers too to develop the creative yet rigorous ways to
1169 capture their processes and outcomes. There is thus a further Catch 22 challenge around
1170 innovation, which our interviewees did not identify but which is easily identifiable from a
1171 research perspective: innovation projects have to provide the compelling evidence that they
1172 work so as to continue to be funded, yet they need to continue to be funded so that such
1173 evidence becomes available or otherwise.

1174

1175 Outside of persevering with topics from the typical health IT range, further research on data
1176 sharing will benefit greatly from opening up to more multidisciplinary work, particularly
1177 from the field of STS (Science and Technology Studies). For instance, findings around “fitting
1178 in” chime with the work of Bruno Latour and Michel Callon on “action-network theory” and
1179 “obligatory passage points” [60]. More broadly, in view of the frequency of use of the
1180 concepts of “challenges” and “drivers” in health services research, we need to subject them
1181 to robust conceptual analysis, also grounded in a variety of empirical findings (See S4 for
1182 considerations arising from the current study). We should, however, remain open to the
1183 possibility that “challenges and drivers” serve us well through their “intuitive” core of
1184 meanings, potentially allowing them to function as “boundary objects” [61]. If this is the
1185 case, we may continue to benefit from the heuristic potential of their somewhat vague and
1186 perspective-dependent conceptualisations in applied work (or at the start of an empirical

study) but must specify our conceptualisations better as a piece of work progresses. As this study has shown, the way we think conceptually about challenges and drivers has surprisingly many implications for what we do about them.

Strengths and limitations of this study

To our knowledge, the broader study of which this sub-study is a part is the most multi-layered study on Electronic Palliative Care Coordination Systems and patient data sharing conducted to date, combining in-depth qualitative work, embedded in findings of pre-existing literature reviews, and also involving quantitative, conceptual and critical arms reported on elsewhere [53, 56-58]. The qualitative element was a particular strength of our work, in a field where this is relatively rare, particularly with the depth of both questioning and analysis achieved here.

The study is, however, a single case study in a single locality in England, concerning a particular type of data sharing – data sharing at the end of life. Some of its findings are unlikely to be generalisable. There are also known aspects of a more comprehensive picture that are missing from our work by virtue of the nature of the case study and its context. For instance, the project relied almost fully on functionalities of pre-existing clinical IT systems. The IT-development work it entailed was limited. The challenges experienced in ground-breaking IT development are thus missing. Also, the project has been taken forward in close collaboration with the local health economy, with many of the links with its decision makers pre-existing or with known routes to forge them. The core stakeholders on the project had the connections and the credibility to secure high level involvement. For many developers

1210 and start-ups in the context of health IT, lacking access to decision makers in the health
1211 service will be one of the biggest, if not the biggest, challenge they are experiencing.
1212

1213 Furthermore, the UK health service – a national health system free at the point of care and
1214 with relatively limited role of the private sector – is not a setting conducive to exploring the
1215 numerous drivers and challenges around market forces, commercialisation and competition
1216 in patient data sharing. Yet such factors may be leading in other countries. It is plausible
1217 that they have a decisive role in a UK context too, even if insufficiently detected by this
1218 study. Competition for instance, often seen as the *sine qua non* of improvement, can,
1219 paradoxically, be stifling in the context of data sharing. On the one hand, commercial
1220 entities in the health service may be unwilling to share their data. On the other, too many
1221 competing data sharing solutions may mean less cross-system sharing as the effort becomes
1222 too dispersed.

1223

1224 Finally, a key aspect of the study was simultaneously a strength and a limitation, i.e. “an
1225 ambivalent force”, to use one of the study’s own concepts: both researchers were members
1226 of the service development and implementation team. On the one hand, this ensured an
1227 insider’s perspective and access to interviewees which would have been impossible to
1228 achieve in other ways. On the other hand, it may have been a source of bias. Numerous
1229 precautions were taken so that such bias is minimised, including explicit introduction at the
1230 start of each interview (conducted by MP, who was a “regular” team member, arguably the
1231 least important member) that we were not conducting an evaluation to show that this was
1232 “a good thing”, but, rather, robust research which aimed to achieve as deep understanding
1233 as possible and move towards solutions from there. The level of challenges we identified

1234 may, paradoxically, be a reassuring thing in one small way. It is unlikely that the picture that
1235 was drawn for us by the interviewees aimed to please us.

1236

1237 **Conclusion**

1238 In summary, data sharing projects hold an immense promise but are hampered by
1239 challenges which, for now, appear to slow down their progress significantly and even block
1240 it completely. We hope that the framework we have offered suggests clear direction for
1241 constructive action, even if some of this action will be beyond the capacity of any single
1242 data sharing team. The vision at the end of the road of significantly improved patient care,
1243 reduced duplication, costs savings and numerous other benefits, almost 60 as per our
1244 findings, is irresistible. Moreover, while challenges may be numerous and complex, no single
1245 barrier appears impossible to overcome. We have good reasons to want to chase the
1246 promise of data sharing with passion and determination.

1247

1248 From the perspective of this study, we are unlikely to reach it for many years to come,
1249 although in the field of innovation one should always be prepared for surprises. A further
1250 source of hope is a positive consequence of the mammoth challenge, and in many contexts
1251 tragedy, of the COVID-19 pandemic. It brought about the “culture change” in digital health
1252 so many were considering fundamental to its accelerated progress. We will be pleased to
1253 have been wrong in our predictions of a long and hard road ahead and observe a dramatic
1254 leap in the success of patient data sharing. In the meantime, with greater knowledge and
1255 realistic appreciation of the challenges and opportunities ahead, data sharing projects can
1256 move from an experience of “wading through treacle” to one of “making haste, slowly”.

1257

1258 MATERIALS AND METHODS

1259 Context of broader study and service development project

1260 This study was part of a broader research, evaluation and impact project – “Prepared to
1261 Share?” [53,55-58] – a mixed methods evaluation of the development, implementation and
1262 outcomes of the Cambridgeshire and Peterborough Clinical Commissioning Group (CCG)
1263 Project for Data Sharing in End of Life Care (the EoLC data sharing project), nested in
1264 broader research on patient data sharing and accompanied by a set of impact activities
1265 (detail in S1).

1266
1267 The study was also embedded in the actual service development and implementation
1268 project, which was initiated in 2012 and officially launched in 2014. The project is ongoing
1269 as “business as usual” in some respects and as an evolving innovation with uncertain
1270 outcomes in others. Both authors have been members of the core project team: SB is the
1271 Clinical Lead for the project; MP was a researcher (2013 – 2017) and a regular member for a
1272 further couple of years. The interaction between the research and service development
1273 project did *not* follow an action research model. The researcher’s role on the service
1274 development team was of an engaged observer, also feeding in policy updates, evidence
1275 from the broader literature, and anonymised evidence from the study if it was relevant to
1276 overcoming obstacles and conflicts.

1277

1278 Design of the current sub-study

1279 The study described in this paper intertwined findings from primary research, namely
1280 qualitative interviews concerning the EoLC data sharing project, with findings from
1281 secondary research, namely four pre-existing literature reviews. The interviews sought to

identify challenges and drivers to the development, implementation and uptake of the EoLC data sharing project. The literature reviews – on the implementation, uptake (adoption, usage), and effectiveness of health information technology and health information exchange [32,41,51,52] – were added so as to query, expand and strengthen the knowledge gained through the analysis of primary data.

The aim of mixing primary and secondary data systematically was to step up the cumulation of knowledge, primarily by strengthening classifications and conceptualisations of challenges and drivers in the literature on HIT and HIE, which, in the words of Greenhalgh et al., are often presented as “long and perhaps unsurprising lists”. [63]

Data sources and data collection

Interview approach

Methodologically and theoretically, the interview schedule and interviewing approach were informed primarily by principles of episodic [64] and realist interviewing [65,66]. As per the former, interviewees were prompted consistently to recount episodes (stories, situations) to illustrate the claims they were making. As per the latter, emphasis was placed on eliciting mechanisms of change or mechanisms sustaining the status quo and the contexts in which these operated. “InterViews” of Brinkmann and Kvale was also a methodological influence [67]. Further details on the interview approach, as well as the core interview schedule, can be found in S1.

1306 *Conduct of interviews*

1307 Interviews were conducted by MP between October 2013 and October 2015. We
1308 acknowledge that the timeframe of data collection relative to the time of reporting raises
1309 concerns about datedness. Our continued involvement in the service development project
1310 confirms that the findings – which are framed at a level of generality which is not impacted
1311 by short-term developments – are still valid. Further observations from this period have also
1312 supported the testing of hypotheses and sharpening of interpretations. We have
1313 deprioritised the reporting of a small number of dated issues (e.g. claims around the need
1314 for “culture change” around the use of health IT, which the COVID-pandemic achieved in a
1315 few short months, if not weeks). Structurally, the delay of reporting represents familiar
1316 problems in academic research: projects running out of funding before being fully reported
1317 on and long turnaround times for peer review.

1318
1319 Interviews were conducted in the service locality (Cambridgeshire and Peterborough CCG,
1320 one of England’s largest Clinical Commissioning Groups covering a population 0.89 million
1321 [62]), mostly in the workplace or house of interviewees. Data collection was spread across
1322 several campaigns reflecting distinct stages of the service development project: initial
1323 development, post-launch in GP practices, stage at which patients might have experienced
1324 care involving the data sharing tools, etc.

1325

1326 *Sample of interviewees*

1327 The sample was purposive, aiming at maximum variation of roles, contexts and participants’
1328 use of the data sharing tools. Details of the variety of recruitment approaches are given in
1329 Table 1. Participants were sent information about the study in advance and encouraged to

ask questions about it. The aims and processes of the study were explained again prior to each interview and participants were reminded that they can interrupt the interview for a break or withdraw from the study at any point, without giving an explanation. Patients and carers were reassured that their care will not be affected in any way by a decision to participate or not. Professionals were reassured that no information will be passed on in any identifiable way to the project leads or colleagues on the service development team. Written informed consent was obtained by all participants. All non-patient/non-carer participants received, as compensation for their time, a £30 gift voucher or the opportunity to donate the equivalent to a charity of their choice.

The total number of interviews was 40, with 45 primary participants. S1 provides details on cases where a “secondary participant” was present (2), more than one participant was interviewed (7), or the same participant was interviewed twice (2). Table 1 breaks down the sample in terms of profile types.

Table 1: Sample characteristics

Role and number of interviewees	Parameters of variation within sample	Unintended features of sample	Recruitment details
Project developers (6)	Leadership and managerial roles (2) IT roles with a focus on tool development (2) IT role with a focus on implementation (1) Educational role (1)		MP was member of the service development team and SB was project clinical lead, which provided direct access to the project team interviewees

Role and number of interviewees	Parameters of variation within sample	Unintended features of sample	Recruitment details
GPs – data sharing initiators (7) (3 further GPs in “out-of-hours and 111” sample and 2 in “Broader project network” sample)	System 4 dominant system D¹ 1 alternative system A1 1 alternative system A2 1 transitioning from a D to an A2 practice Use of tools for end of life care data sharing 1 – high use 3 – use 1 – uses a different tool 2 – do not use Area 2 – affluent local village 2 – remote rural, deprived 1 – town centre, affluent 1 – inner city, deprived 1 – suburban Gender 4 female 3 male Career stage 3 early career 2 mid-career 2 experienced	2 participants with leadership roles in end of life care 1 participant with experience of a serious adverse event in end of life care in their practice 3 participants engaged in their own research 2 participants with Local Commissioning Group roles 1 participant working on another data sharing project	45 expressions of interest (through response slip accompanying survey to all local GPs) 14 contacted 7 agreed and interviewed 7 did not respond
Other healthcare professionals – data sharing recipients (15)	Out-of-hours and 111 (telephone triage and advice line) 3 GPs (1 also working in-hours; 2 male, 1 female; 1 mid-career, 2 experienced) 3 nurses (all also working in-hours – 2 in general practices and 1 in		Information in email bulletins of the out-of-hours service Reaching out to participants in awareness raising events and meetings with pilot users Approaching members of the Stakeholder Group

¹ D for “dominant” and A for “alternative”, with two versions A1 (old) and A2 (new).

Role and number of interviewees	Parameters of variation within sample	Unintended features of sample	Recruitment details
	community; 3 female; 1 mid-career, 2 experienced) Palliative care specialists 3 consultants (2 hospital, 1 hospice; 1 with an IT role) 3 nurses (2 hospital, 1 community) Hospital staff 4 of the palliative care specialists (see above) 1 Accident & Emergency, consultant 1 Medicine for the Elderly, consultant 1 GP practice administrator		
Patient and carers (9)	Patients/ carers 2 patients 2 current carers 5 bereaved carers Perceptions of data sharing b/n health professionals (from response slips in recruitment pack) 2 – sharing varies 2 – sharing good 1 – do not share enough 1 – question not completed 3 – no separate response slip, as joining main interviewee Age 50s – 2 60s – 3 70s – 3 80s – 1	Patients of 1 practice. However, had quite varied experiences of data sharing and used a broad variety of services in different parts of the locality. See column to the right for decision to discontinue patient interviews earlier than planned.	Recruitment through interviewed GPs. Recruitment materials developed with strong user support. Several participants commented that the experiences described in the vignettes in the recruitment booklet were almost like their own. 8 response slips received. On phoning, 2 patients responded that it was not a good time to participate in research. The remaining 6 were interviewed, along with 3 further family members. Recruitment of patients and carers was

Role and number of interviewees	Parameters of variation within sample	Unintended features of sample	Recruitment details
	Gender 2 male 7 female Patient condition (for interviewed patients) 2 – multimorbidity Carer relationship to patient 3 daughter 2 wife 1 husband 1 son-in-law		discontinued after having interviewed 9 in 5 interviews (original intention was for 24 participants, single person interviews). Data sharing was showing to be a minor and vague consideration relative to their broader experience of illness, healthcare in general and end of life care in particular, with strongly positive opinions expressed in its favour.
Broader project network (members of the Stakeholder Group and key informants from broader context) (8)	5 commissioners (project managers or clinical leads in Clinical Commissioning Group or Local Commissioning Groups) 2 Information Governance/medico-legal issues specialists 1 IT manager		Recruitment through Stakeholder Group or opportunistically, following meetings or email exchanges aiming to facilitate the service development project

1347

1348 *Resulting interview data*

1349 The interviews lasted between 35 m and 1h 36 m; average length 56 m; total length of the

1350 recorded interviews (36) 33.6 hours. A professional transcriber transcribed verbatim 34

1351 interviews, amounting to 518 pages and > 285 000 words. Four participants (one patient,

1352 one nurse and two key informants with professional roles involving significant familiarity

1353 with the law) preferred not to be audio-recorded. The two final interviews, conducted after

1354 heavy saturation was reached, were transcribed verbatim by the first author only in the
1355 sections we intended to use for reporting.

1356

1357 *Literature reviews*

1358 The literature reviews serving to complement/ challenge the primary data and ensure
1359 strong cumulation of knowledge were selected as the most relevant and detailed reviews
1360 from our collection of HIE and HIT papers and extensive (though not systematic) literature
1361 searches on HIE. Two of the reviews, both systematic, were on HIE [32, 41]. The other two,
1362 both with a strong focus on theory, were on the broader topic of HIT adoption and use
1363 [51,52]. The overlap of issues in HIT and HIE is significant, while existing work on bridging
1364 them is not. The reviews covered 135 source studies, mostly primary studies but also
1365 reviews.

1366

1367 **Data analysis**

1368 Transcripts were checked against the audio-recording, corrected, anonymised and
1369 annotated by the first author, as part of a process of immersion in the data. An extensive
1370 thematic analysis was undertaken after the project team interviews (nine with six team
1371 members) for a “Lessons Learnt” document for the service development team. It provided
1372 an initial framework of considerations, which was then expanded through parameters
1373 identified in the literature reviews. The resulting framework was used to analyse the
1374 remaining interviews,[68] with an added emphasis on specifying mechanisms (M), contexts
1375 (C) and outcomes (O) and linking them into CMO configurations (not reported on here).
1376 Coding was also consistently “pluralist”: considerations were coded under a broad range of
1377 parameters, often three to five, rather than under one or two most fitting categories. This

1378 approach is informed by the philosophy of science and work on classification of Dupré [69,
1379 70].

1380

1381 With the exception of introductory and concluding sections and, in the case of patient and
1382 carer interviews, extended descriptions of the illness experience, practically every line of the
1383 interviews was coded. Both the text of the literature reviews and tables representing source
1384 studies were analysed. Coding was performed in “meaningful chunks” of variable length,
1385 from one to two words to whole paragraphs, depending on the degree to which the goals of
1386 the analysis, pre-existing ideas, and our emerging understanding prompted us to code at a
1387 more or less granular level. The QSR NVivo software (versions 11 and 12) was used.

1388 The above stage of analysis (2nd, analysis for the Lessons Learnt exercise counted as 1st)
1389 resulted in a framework of over 1,800 challenges and drivers. This was then condensed to a
1390 more economical, but still extensive, framework of over 800 components (NVivo coding
1391 again, 3rd stage). Following that, we mapped challenges and drivers and their best
1392 illustrative quotes in Microsoft Excel, with particular attention paid to creating “dyads”, i.e.
1393 pairs of challenges and drivers, which began to reveal some of the concepts reported on
1394 here (4th stage). We also developed a high order framework (of 29 components) organised
1395 around the IT solution, the project team, health professionals, patients, contextual and
1396 temporal parameters, and a set of “co-created” parameters that did not have a primary
1397 belonging. Each of the components was accompanied by a numerical coefficient of the ratio
1398 of challenges and drivers within it, on the basis of which key challenges and key drivers were
1399 singled out (5th stage). As we still felt we had not achieved the parsimony and clarity of
1400 recommendations for practical action we were seeking, we followed some of the threads
1401 from the work on creating dyads of challenges and drivers. We recoded, in NVivo, the 800+

1402 challenges and drivers from stage 3 in terms of more formal characteristics, such as whether
1403 a challenge or a driver appeared in a dyad or stood alone and what was the nature of the
1404 relationship between them if they came in dyads (6th stage). This process was felt to have
1405 delivered a powerful higher order framework. Finally, we re-attributed the illustrative
1406 quotes from stage 4 to the new framework and refined the latter (in Microsoft Word, 7th
1407 stage). Each of these stages involved multiple internal iterations.

1408
1409 Findings from the four literature reviews were incorporated into the 800+ and 1,800+
1410 frameworks but later contributed little to the higher order organising principles we are
1411 proposing. See Box 2 in S4 for “key categories” of challenges, drivers and ambivalent forces
1412 as identified in the four literature reviews.

1413

1414 **Ethics approval**

1415 NRES Committee East of England – Cambridge East approved the study (Ref 13/EE/0291).

1416 Written informed consent was obtained from all interviewees.

1417

1418 **Patient and Public Involvement (PPI)**

1419 The study was supported by a study-specific PPI group. It had six members, five female and
1420 one male, all with personal experience of palliative and end of life care of their loved ones.

1421 Feedback by the group transformed the patient recruitment materials, by making them far
1422 simpler, easier to understand and personal as opposed to legalistic and formulaic. In some
1423 respects, the new information materials were at variance with existing guidance. The Local
1424 Research Ethics Committee was, however, very positive about them and only requested that
1425 we re-position some of the information. Our users also contributed to clarifying and

1426 simplifying questions in the interview schedule as well as provided feedback on one of the
1427 key papers of the study. S1 reports on user involvement using the GRIPP2 short form.

1428

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1430 The funders had no role in study design, data collection and analysis, decision to publish, or
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1432

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Supporting information/ Supplementary files:

S1: More on methods

S2: Further quotes

S3: Recommendations for action

S4: Conceptualising challenges and drivers

1681 **Author statement**

1682 Both authors conceived of the “Prepared to Share?” study and developed its design. MP
1683 collected the data, performed the data analysis and drafted the manuscript. Both authors
1684 edited numerous versions of this manuscript.

1685

1686 **Data statement**

1687 A significant subset of the interviews are with members of the project team and with
1688 individuals with leadership roles in the local health economy. Sharing the transcripts of such
1689 interviews can easily compromise participants’ anonymity. Extensive quotes are provided in
1690 S2. Further data can be provided upon reasonable request.

1691

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1703

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1705 Both authors are members of the project development team for the Cambridgeshire &
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