Between "the best way to deliver patient care" and "chaos and low clinical value": General Practitioners' and Practice Managers' views on data sharing

Abstract

Background: Patient data sharing is invested with high expectations of improving quality of care, patient safety and cost-effectiveness, yet continuously fails to meet them. In the UK, General Practitioners (GPs) and Practice Managers (PMs) are key to enabling it, with the primary patient record held in GP practices. We explored GPs' and PMs' familiarity, engagement with and perceptions of patient data sharing.

Methods: Cross sectional survey sent to all GPs and PMs (637) in all 107 general practices in England's second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG, population 0.86 million.

Results: 405 responses were received (64% response rate). Familiarity and engagement were highest for local frail elderly and end of life care projects (>76% had used at various levels). The greatest difference in use concerned the now suspended *care.data*: PMs had odds of reporting use 75 times higher than GP partners (95% CI 27 to 211). Patients' confusion and improved coordination were, respectively, the most pronounced challenge and benefit. Frequency of discussions with patients varied with IT competence (OR 4.2 for most competent users relative to least, 95% CI 1.7 to 10.7) and clinical system (OR 0.3, 95% CI 0.1 to 0.5). Respondents who rated their IT competence as highest reported patient reservations more frequently (OR 3.3, 95% CI 1.5 to 7.6), as did PMs and those with higher perceptions of the challenges of data sharing.

Conclusions: Familiarity with and use of data sharing projects was high among GPs and PMs. Both their individual and organisational characteristics were associated with the reported frequency of discussions and patients' responses, in contrast to expectations of equity and autonomy in patient decision making about data sharing.

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INTRODUCTION

In a world of ubiquitous IT-connectivity and fragmented patient care, data sharing, also known as Health Information Exchange (HIE), is envisaged as the IT-backbone to the "seamless integration" of health and social care services. The interest in it is enormous, as well as its expected benefits:[1-4] improved clinical decision making enabled by accessing a more complete longitudinal patient record;[5,1,6] improved coordination and continuity of care;[7-9] reduction in duplicate investigations[5,10-15] and hospital admissions;[5,14-19] improved patient safety[20] and enhanced experience, involvement and empowerment;[1,21] efficiency gains[22] and cost-savings.[11,14,15,23-26] The number of HIE initiatives is rapidly growing. For instance, a 2012 US survey found that 1,398 hospitals (30%) and 23,341 ambulatory practices (10%) were participating in 119 operational HIE projects, in comparison to 14% of hospitals, 3% of practices and 75 projects two years earlier two years earlier.[27]

Few systems, however, achieve the advanced and easy to-use-functionalities represented in visions for mature HIE.[24,28,29] The challenges of development, implementation uptake and sustainability are significant, the findings about outcomes often disappointing.[2, 22, 24, 27, 30-38] A recent systematic review[24] suggests that HIE tools are used to a limited extent, typically in between 2% to 10% of patient visits, and that their impact on outcomes is largely unknown beyond HIE "probably reduces emergency department usage and costs in some cases".

In the UK, the 2013 Information Governance Review[1] introduced a new IG principle: "the duty to share information can be as important as the duty to protect patient confidentiality". Improved patient data sharing is high on the National Health Service (NHS) agenda, a priority in the "Five Year Forward View",[39] "Personalised Health and Care Plan 2020",[40] "General Practice Forward View",[41] and recent announcements of "unprecedented" NHS investment.[42] In the UK, GP practices are where the primary patient record is held and clinical IT use is best embedded. As of 2016, 98% of GPs are using an electronic medical record in daily practice routinely.[43] GP and Practice Manager (PM) engagement with data sharing projects is thus crucial to progress in the field. To our knowledge, no similar survey addressing familiarity, engagement with and perceptions of data sharing amongst UK GPs and PMs has been published.

The survey was part of a research-evaluation study of the Cambridgeshire & Peterborough Project for Data Sharing in End of Life Care (the C&P Project), initiated in 2012 as an Electronic Palliative Care Coordination System (EPaCCS) project.[44] It aimed to find out:

1) What are GPs' and PMs' self-reported levels of familiarity with and use of different data sharing tools?

2) How do GPs and PMs perceive the benefits and challenges of patient data sharing?

3) What are GPs' and PMs' perceptions of patients' attitudes to data sharing?

4) What respondent characteristics are associated with 1-3 above?

The study was carried out in England's second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG, covering a population 0.86 million.

METHODS

Survey design and contents

We designed a survey on the basis of 1) the literature on HIE and Health Information Technology (HIT) implementation; 2) discussions at meetings of the C&P Project team; 3) discussions with members of the study Lay User Group; and interviews with project developers and stakeholder group members. Over 30 individuals (health professionals, IT staff, commissioners, managers, CCG communications officers, etc.) provided comments on survey versions, including four GPs and four PMs who piloted it. The final GP and PM surveys were largely identical, with some rephrasing and tailored questions (GP version in Appendix 1). Box 1 outlines the data sharing initiatives enquired about.

Box 1: Data sharing projects

1. **Summary Care Record** – an electronic record which contains information about medicines, allergies and adverse reactions and is available for over 96% of the population of England.
 http://systems.hscic.gov.uk/scr/patients/what
 http://www.hscic.gov.uk/article/6476/Summary-Care-Record-rolled-out-to-community-pharmacists

2. **eDSM (the Enhanced Data Sharing Model)** – a model of data sharing introduced in Aug 2013 in SystmOne, the dominant clinical IT system in the area, which resulted in a widespread campaign for consenting patients.
 http://www.digitalhealth.net/news/28231/tpp-rolls-out-new-sharing-model

3. **Frail, Elderly and High Risk Patients/ Multidisciplinary Team (MDT) project** – a local project using a standardised, detailed template (for data entry) and "view" (for read-only access) to create a shared care summary for frail, elderly or high risk patients, with a core aim of reducing unplanned hospital admissions. Highly prominent and incentivised around the time of the survey.

4. **End of Life Care Project, Cambridge** – a local project using a template and view to create a shared care summary for patients believed to be approaching the end of their life. An EPaCCS (Electronic Palliative Care Coordination System) solution. Highly prominent and, in some LCGs, incentivised at the time of the survey.

5. **End of Life Care Project, Peterborough** – a local project initiated prior to the Cambridge one, using a slightly different template but the same view and based around a Palliative Care Coordination Centre. The two projects were fully integrated after the survey was sent out.

6. **Medical Interoperability Gateway** – one of the pre-eminent commercial data sharing solutions in the UK, not available in the study area at the time of the survey.
 http://www.healthcaregateway.co.uk/products

7. **Urgent Care Dashboard** – a local project representing, at a practice level, unscheduled care contacts and admissions for the practice patients.

8. **Care.data** – a project of the UK Government for extracting data from the records of all GP practices, using a default opt-in model. Led to a media outrage as a result of concerns about confidentiality and potential commercial uses of the data. Later suspsended.

9. **Unscheduled care summaries** – locally standardised views for use in out of hours and emergency settings, including the End of Life Care Summary, Health & Care Summary and Plan, and Medical Problems and Drugs view.

We investigated the relationship between responses and nine independent variables: practice clinical IT system, GP perceived competence in using it, Caldicott (information governance) Guardian status, professional role, years of experience, gender, Local Commissioning Group (LCG), time point of response (original survey, first or second reminder) and efficiency of response (speed of returning the survey). Information about the first five variables was solicited in the questionnaire and added subsequently about the remainder.

Sampling

A pre-existing database of GPs, PMs and practice addresses held by the team was updated with information from practice websites, the national NHS Choices website, and contacting practices. Information about the practice clinical IT systems was provided by the CCG IT team. Over time, staff numbers remained reasonably stable, but individuals changed frequently: for instance, a phone-in exercise 6 months after finalising the database, in August 2014, found that 69 of the GPs and PMs we had sent letters to had moved on. Flowchart 1 (Appendix 2) details the changing GP and PM populations. We use 542 GPs, 95 PMs and 637 total as denominators in calculating response rates, to include all individuals who were sent the original survey letter and were still in their practices as of August 2014, as well as individuals who had left the practice but returned the survey.

Survey administration and context

The first mailing in April 2014 comprised a paper copy of the survey with an accompanying cover letter and freepost reply envelope. Each survey had a unique alpha-numeric code, which participants could use to complete the survey online and which we used to identify non-respondents. This code was subsequently cut off by an administrative assistant (SSB). Reminders were sent in May and August, in both cases about 2 weeks after the last response had been received. The first reminder included a "no further reminders and reasons for non-response" slip for those declining to participate and the opportunity to enter a prize draw of 3 x £100. The final reminder included a brief note handwritten by MP.

Data quality

Data were entered by SSB and MP, who checked each other's entries against the original questionnaires and minimal errors were corrected. Missing data in the nine independent variables (44% of respondents, 0.5% to 10% of variables) were accounted for using multiple imputation by chained equations [45-47] in Stata v13.1 (StataCorp, College Station, TX). Imputed outcome variables were not used in analysis [48]. Binary variables were imputed using logistic regression, while continuous and ordinal variables were imputed using predictive mean matching [49]. Results from the ten imputed datasets were combined using Rubin's rules.[45]

Analysis

Descriptive statistics and cross-tabulations aimed at preliminary exploration of associations were obtained in SPSS v22 (IBM SPSS Statistics). "Perception of benefits" and "perception of challenges" scores were computed, representing the mean sum of the values chosen for agreement/ disagreement with statements about the likelihood of a particular benefit/ challenge materialising. The benefits/ challenges were unweighted and normalised to a neutral point of 0 (the survey 'unsure' point was 3).

The association between nine respondent and organisational characteristics (see *Survey design and contents* above) and the following dependent variables were investigated: use of each of the nine data sharing tools included in the survey; frequency of discussions of data sharing with patients; frequency of two measures of perceived patients' endorsement of data sharing; and frequency of four measures of perceived patients' reservations about data sharing. Perceptions of benefits and perceptions of challenges scores were also included in the models for the latter three variables. Patient endorsement of data sharing was considered to be indicated by responses of "Yes, I agree" to data sharing and "I thought you were doing it already?!". Patient reservations were considered to be indicated by responses of "No, I do not agree" to having my data shared, "No, I am strongly opposed", "I am confused" and "Why are you asking me again?!". See Appendix 2 for four further higher level groupings of response options.

Exploratory analysis suggested substantial clustering in the answers given on related questions by each respondent. To account for this clustering, we used hierarchical logistic regression to investigate the association between respondent and organisational characteristic and the dependent variables. Initial models included interactions between each characteristic and the particular response, for example the particular data sharing tool. Interactions which were not statistically significant ($p>0.1$) in any imputed dataset were removed as were terms relating to the timing of survey responses.

Free text responses were first coded in NVivo v9 (QSR International), with the final classification completed in Word.

RESULTS

Response rate and sample characteristics

Table 1 shows the response rate after each of the three mailouts. First responses were received in April 2014 and the majority of final responses in September 2014; a small number of replies continued until February 2015. Four surveys were completed online. Response rate was estimated at 63.6%: 62.4% of GPs and 70.5% of PMs. With the frequent changes of GP practice staff, this is likely to represent 57.3% of the current GP and 63.2% of PM populations (Flowchart 1, Appendix 2).

With regard to available population data (LCG and practice IT system), the sample was similar to the total population, with some differences observed in the proportion of the two EMIS user types (Web and LV) for which data sharing is less straightforward in the study locality (Table 2).

Table 1: Response rate by survey administration phase

Survey administration phase	Main features	Respondents number % of total responses within group			Minimal data respondents		
		Total	GPs	PMs	Total	GPs	PMs
Original mailout Apr 14	Personalised Signed by PI and RA	**40.2% (163)**	39.3% (133)	44.8% (30)			
1st reminder May 14	Prize draw Personalised Signed by PI and RA "no further reminders and reasons for non-response" slip added	**24.9% (101)**	24.0% (81)	29.9% (20)	**13**	11	2
2nd reminder Aug 14	Handwritten on study paper or small colour sheets	**34.1% (138)**	35.8% (121)	25.4% (17)			
Missing information		**0.7% (3)**	0.9% (3)	0			
Total		**100% 405**	100% 338	100% 67	**13**	11	2

Table 2: Sample composition and indicators of representativeness

CHARACTERISTIC	GPs		PMs		Total	
	Respondents' value	Comparator: reference value or alternative measure [*]	Respondents' value	Comparator: reference value or alternative measure	Respondents' value	Comparator: reference value or alternative measure
No **%**	338 83.5% of survey respondents	542 85.1% of reference population	67 16.5% of survey respondents	95 14.9% of reference population	405 all survey respondents	637 reference population
ROLE SUBTYPE						
Partner	207 61.2%	151[†] 27.9%	NA	GPs only		
Salaried	73 21.6%	41 7.6%	NA	GPs only		
Locum	4 1.2%	9 1.7%	NA	GPs only		
Other	6 1.8%	3 0.6%	NA	GPs only		
Missing	48 14.2%	338 62.4%				
LOCAL COMMISSIONING GROUP [‡]						
LCG 1	97 29.0%	145 26.8 %	17 25.4%	25 26.3%	114 28.4%	170 26.7%
LCG 2	43 12.9%	58 10.7%	6 9.0%	9 9.5%	49 12.2%	67 10.5%
LCG 3	46 13.8%	76 14.0%	13 19.4%	17 17.9%	59 14.7%	93 14.6%
LCG 4	27 8.1%	45 8.3%	5 7.5%	9 9.5%	32 8.0%	54 8.5%
LCG 5	38 11.4%	57 10.5%	6 9.0%	9 9.5%	44 11%	66 10.4%
LCG 6	13 3.9%	25 4.6%	4 6.0%	4 4.2%	17 4.2%	29 4.6%
LCG 7	31 9.3%	71 13.1%	10 14.9%	14 14.7%	41 10.2%	85 13.3%
LCG 8	39 11.7%	65 12.0%	6 9.0%	8 8.4%	45 11.2%	73 11.5%
Missing	4		0		4	
CLINICAL IT SYSTEM						
SystmOne	241 71.3%	385[§] 71.0%	52 77.6%	69 72.6%	293 72.3%	454 71.3%
EMIS Web	49 14.5%	61 11.3%	10 14.9%	9 9.5%	59 14.6%	70 11.0%
EMIS LV	38	85	3	15	41	100

[**] We use 'reference value' to mean a highly reliable comparison measure, usually taken from the whole population of interest. We use 'alternative measures' to mean comparators derived from an alternative sample. They may be less reliable than the survey values, but are the only comparator we can currently offer (source indicated). Alternative measures are in grey.

[†] Information from practice websites, as collected for the original database of all local GPs and PMs (Feb 2014). In the majority of cases (62%), information about partner status was not provided.

[‡] LCG 1 – CATCH, LCG 2 – CamHealth, LCG 3 – Hunts Care Partners, LCG 4 – Hunts Health, LCG 5 – Isle of Ely, LCG 6 – Wisbech, LCG 7 – Peterborough, LCG 8 – Borderline.

[§] Data provided by the CCG Primary Care Information Team, Sep 2014 update.

	GPs		PMs		Total	
CHARACTERISTIC	**Respondents' value**	**Comparator: reference value or** alternative measure [*]	**Respondents' value**	**Comparator: reference value or** alternative measure	**Respondents' value**	**Comparator: reference value or** alternative measure
	11.2%	15.7%	4.5%	15.8%	10.1%	15.7%
Vision	7 2.1%	11 2.0%	2 3.0%	2 2.1%	9 2.2%	13 2.0%
Changing or missing	3					
SELF-REPORTED IT COMPETENCE						
No	338	542	67	95	405	637
Familiar with basic functions	73 21.6%	NA	NA		GPs only	
Competent user	189 55.9%	NA	NA		GPs only	
Use more functions than most	59 17.5%	NA	NA		GPs only	
Missing	17 5.0%					
CALDICOTT GUARDIAN STATUS						
Yes	60 17.8%	NA	13 19.4%	NA	73 18.0%	107[**] 16.8%
No	272 80.5%	NA	51 76.1%	NA	323 79.8%	530 83.2%
Not sure or missing	6		3 4.5%		9 2.2%	
YEARS OF EXPERIENCE IN ROLE						
0-4	37 10.9%	1[††] 0.2%	28 43.1%	NA	65 16.0%	only GP comparator
5-9	60 17.8%	21 5.8%	9 13.4%	NA	69 17.0%	only GP comparator
10-19	104 30.8%	118 32.7%	15 22.4%	NA	119 29.4%	only GP comparator
20+	113 33.4%	221 61.2%	14 20.9%	NA	127 31.4%	only GP comparator
Missing	24 7.1%	181 33.4%	1 1.5%	NA	25 6.2%	
GENDER (externally added)						
Male	145 42.9%	235 43.4%	14 20.9%	19 20.0%	159 39.3%	254 39.9%
Female	160 47.3%	241 44.5%	47 70.1%	69 72.6%	207 51.1%	310 48.7%
Missing	33 9.8%	66 12.2%	6 9.0%	7 7.4%	39 6.6%	73 11.5%

[**] One for each local practice.

[††] Alternative measure using information on graduation/ registration of GPs from practice websites. Suggests a different profile of local GPs than the study sample, with a much smaller number of doctors at the beginning of their careers. Information was missing in 33% of cases (vs. 7% in the study). It is also possible that years of experience have been highlighted for more experienced GPs, as a way of reassuring patients of the care they will receive in a particular practice.

Descriptive findings

Familiarity with and use of data sharing tools

The majority of respondents have used or recognised all nine data sharing projects with the exception of the Medical Interoperability Gateway (MIG), which was unfamiliar to 81.2%. The most familiar and used tools were local projects addressing the needs of frail elderly patients (1.5% "never heard of" and 89.4% have used at variable levels) and End of Life Care patients (3.5% / 4.7% "never heard of" and 76.2% / 77.9% have used, for Cambridgeshire and Peterborough respectively). After the MIG, the second least familiar project was *care.data* (unheard of by 30.9%, primarily GPs) (Table 3).

Table 3: Familiarity and use of data sharing tools

Data sharing project	"Never heard of"						"Responses indicating use"					
	GPs		PMs		Total		GPs		PMs		Total	
Summary care record	2	0.6%	0	0.0%	2	0.5%	188	55.6%	51	76.1%	239	59.0%
Enhanced Data Sharing Model	99	29.3%	3	4.5%	102	25.2%	106	31.4%	48	71.6%	154	38.0%
Frail elderly project	6	1.8%	0	0.0%	6	1.5%	298	88.2%	64	95.5%	362	89.4%
End of Life Care Project, Cambridge	10	3.8%	1	2.0%	11	3.5%	194	73.5%	46	90.2%	240	76.2%
End of Life Care Project, Peterborough	3	4.3%	1	6.3%	4	4.7%	56	80.0%	11	68.8%	67	77.9%
Medical Interoperability Gateway	283	83.7%	46	68.7%	329	81.2%	3	0.9%	5	7.5%	8	2.0%
Care.data	123	36.4%	2	3.0%	125	30.9%	40	11.8%	48	71.6%	88	21.7%
Urgent Care Dashboard	25	7.4%	0	0.0%	25	6.2%	208	61.5%	62	92.5%	270	66.7%
Unscheduled care summaries	59	17.5%	13	19.4%	72	17.8%	176	52.1%	48	71.6%	224	55.3%

Perceptions of benefits and challenges of data sharing

Overall, GPs and PMs saw both the benefits and challenges of data sharing as somewhat likely to materialise: means were 0.53 and 0.56 respectively (0 was the neutral point, range -2 to 2, SD 0.73 and 0.53). The challenges perceived as most pronounced were patients' confusion (mean 1.12) and the anxiety created by media coverage (1.03). The benefit perceived as most likely was improved coordination of care (0.96). The least expected benefit was cost reduction (- 0.01), Table 4.

Table 4: Perceptions of benefits and challenges of data sharing

Statements are ordered by mean value, normalised to 0 (0 is neutral, values between -2 and 0 correspond to the benefit/ challenge considered unlikely and/or not a concern and values between 0 and +2 correspond to the benefit/ challenge considered likely and/or a concern). The final column represents benefits in green and challenges in red, for a general overview of what takes priority in perceptions.

Potential benefit	Potential challenge	No	Mean and SD	
	Patients are confused	401	1.12 (0.87)	🟥
	Media coverage has created anxiety	401	1.03 (0.81)	🟥
Coordination of care ↑		400	0.96 (0.83)	🟩
Work within broad MDT team ↑		399	0.79 (0.85)	🟩
Clinical decision making ↑		400	0.78 (0.90)	🟩
Work within immediate team ↑		398	0.73 (0.86)	🟩
	Medical-legal issues	400	0.65 (0.88)	🟥
Patient experience ↑		400	0.64 (0.91)	🟩
Unnecessary interventions ↓		400	0.63 (0.87)	🟩
	Information governance	397	0.59 (0.88)	🟥
	Time constraints will limit sharing own data	401	0.53 (0.91)	🟥
	Time constraints will limit using shared data	400	0.49 (0.90)	🟥
	Information quality	397	0.40 (0.92)	🟥
Avoidable admissions ↓		399	0.38 (0.94)	🟩
Data re-entry ↓		399	0.31 (1.03)	🟩
	Records will be getting too much attention	399	0.19 (0.98)	🟥
	Data re-entry ↑	401	0.08 (0.96)	🟥
Length of hospital stay ↓		399	0.03 (0.88)	🟩
Costs ↓		399	-0.01 (0.96)	🟩

Frequency of discussions about data sharing and patient response types

At the time of the survey, which coincided with intense work on several data sharing projects (see Box 1), 89.1% (361) of respondents discussed data sharing with patients "occasionally" or more frequently: 58.0% (235) "occasionally", 23.5% (95)"on most days", 7.7% (31) "on most weeks" and 7.4% (30) "not at all".

The most frequently reported patient response was agreement to sharing: 59.5% (241) of respondents reported hearing that often or very often, followed by "I thought you were doing it already" (38.8%, 157), confusion (32.8%, 133), "Why are you asking me again" (19.5%, 79), and not consenting to sharing (12.6%, 51). Strong objection to sharing was the least frequently reported patient response (9.6%, 39).

Free text responses

While there were some highly positive comments (e.g. "the best way to deliver patient care"), the great majority of free text comments were negative ("ill thought-out", "a mess", "complete chaos and low clinical value!") or at least hesitant ("the crucial thing is who the data is shared with and why"). Overall, extended negative comments did not challenge data sharing in principle, but expressed frustration with the ways in which particular initiatives have been set up and overlapped, in the context of unrelenting pressures in general practice (Appendix 2).

Logistic regression findings

IT-infrastructure

While locally data sharing is easier or only possible under the dominant system for five projects (Enhanced Data Sharing Model, the two End of life Care projects, one in each locality, the Frail Elderly project, and CCG health and care summaries), clinical system was found to be associated with use of the EDSM (OR 0.03, 95% CI 0.01 to 0.09), Cambs End of Life Care (OR 0.3, 95% CI 0.1 to 0.7), and Summary Care Record (OR 0.4, 95% CI 0.2 to 0.7) (Figure A1 B, Appendix 2).

Staff using the dominant system were more likely to have discussions about data sharing than those using alternative clinical IT systems (OR other vs SystmOne 0.3, 95% CI 0.1 to 0.5) (Table A1, Appendix 2).

Clinical IT system did not appear to be associated with the frequency of reporting patient endorsement of data sharing (p>0.1, Table A2, Appendix 2), but was associated with the frequency of different types of negative responses. Respondents from practices using the dominant system were more likely to report patients responding with "Why are you asking me again?!" (OR 0.3 for users of alternative systems, 95% CI 0.1 to 0.6). Respondents from practices using alternative systems were more likely to report responses of 'strongly opposed' (OR 2.5, 95% CI 1.0 to 6.1) (Table A3, Appendix 2).

IT and IG knowledge

GPs who perceived themselves as more competent in using their clinical IT systems were more likely to use data sharing tools. The main difference was between users who reported basic skills and the rest, rather than between competent users and advanced users (OR competent vs. basic skills 2.5, 95% CI 1.5 to 4.0; OR advanced vs. basic skills 4.0, 95% CI 2.1 to 7.7, Figure A1 F, Appendix 2).

More competent users were more likely to report frequent discussions about data sharing, with an apparent dose-response relationship (OR 2.2, 95% CI 1.0 to 4.5 for those who self-rated as competent users and 4.2, 95% CI 1.7 to 10.7 for those who self-rated highest, Table A1, Appendix 2). No association was found between clinical IT competence and reports of patient endorsement of data sharing. However, advanced users were more likely to report patient reservations (OR 3.3, 95% CI 1.5 to 7.6) (Table A3, Appendix 2).

Caldicott Guardians were found to be more likely than respondents not performing this information governance role to use data sharing tools (OR 2.4, 95% CI 1.5 to 3.8, Figure A1 E, Appendix 2). Caldicott Guardian status did not, however, appear to be associated with frequency of discussions or patient response types.

Demographics

Women were more likely than men to use the End of Life Cambs data sharing tool (OR 2.9, 95% CI 1.3 to 6.4, Figure A1 A) and, more tentatively, the Frail Elderly and Summary Care Record (ORs 2.2, 95% CI 1.1 to 4.6, and 2.5, 95% CI 1.0 to 6.5, respectively). Gender did not seem to be associated with the use of the remainder of the tools, the frequency of discussions about data sharing, and patient response types.

Respondents with >=10 years of experience were less likely to use data sharing tools than those with 0-9 years of experience (OR 0.4, 95% CI 0.3 to 0.6, Figure A1 D, Appendix 2). Years of experience were not associated with frequency of discussions about data sharing or patient response types.

Organisational context

There was weak evidence of a difference in the use of data sharing tools by LCG, with different trends for different tools (p=0.02) (Figure A2, Appendix 2).

Role

PMs were more likely to use data sharing tools than GP partners, while non-partner GPs were typically less likely to use them (Figure A1 C, Appendix 2). The single largest difference was for *care.data*: PMs had odds of reporting use 75 times (95% CI 27 to 211) higher than GP partners. This may reflect differences in the scope of the question, as PMs were asked about their practice's involvement, while GPs were asked about their personal use.

There was weak evidence of differences in the frequency of discussions by role (p=0.04, Table A1, Appendix 2), with non-partner GPs having such discussions less frequently. However, PMs were

more likely than GP partners to report patient responses of "I thought you were doing it already" (OR 2.8, 95% CI 1.0 to 7.6) and much more likely to report patient reservations than GP partners (OR 18.0, 95% CI 7.9 to 41.3) (Tables A2 and A3, Appendix 2).

Benefits / challenges perceptions as an independent variable

Respondents' perceptions of the benefits and challenges of data sharing did not appear to have an impact on how likely they were to discuss data sharing.

There was weak evidence (p=0.055) that the frequency of reporting patient endorsement was higher amongst those with a higher perception of the benefits of data sharing. It did not appear to be associated with perceptions of the challenges of data sharing (p=0.89) (Table A2, Appendix 2).

The frequency of reporting patient reservations about data sharing was associated with a higher perception of the challenges of data sharing (OR for a 1-point increase in challenges perception score 3.4, 95% CI 2.1 to 5.6). It did not appear to vary by perception of the benefits of data sharing (p>0.1) (Table A3, Appendix 2).

Timing

The timing variables (phase – original mailout, first or second reminder, and efficiency of return of the survey) was largely unrelated to the nature of the responses received. There was a suggestion of a difference in the frequency of discussions of data sharing by timing of response (p=0.025), with those who responded after the first reminder less likely to discuss data sharing with their patients (see Table A1, Appendix 2).

DISCUSSION

Summary of key findings

To our knowledge, no similar survey-based study has been published of GPs' and PMs' familiarity with, use and perceptions of patient data sharing. This is in spite of the growing number of initiatives, the policy commitment, and the key role of general practice in enabling patient data to be shared. We found GPs and PMs to be familiar and engaged with data sharing projects, particularly with local CCG projects on frail elderly patients and end of life care. Professional role emerged as the strongest predictor of use of data sharing tools. In its extreme, PMs had odds of reporting use of *care.data* 73 times higher than GP partners. While this may reflect primarily the different scope of

the question, with PMs asked about their practice's involvement and GPs about their own, it also suggests that data sharing projects may have a low real or perceived clinical utility and end up being driven at an administrative level. In contrast, clinical IT system appeared a weaker predictor of use of data sharing tools than expected. Advantages were detected for users of the dominant system, who can access more and richer tools and do so far more easily, but these were less pronounced than hypothesised. Workarounds are available for users of the alternative systems. Challenges of action for users of the dominant system (e.g. asking for patient consent, finding time, recognising that limitations of service capacity may invalidate even the most carefully developed care plan) may be almost as problematic as the barriers to action for users of alternative systems. Importantly, claims about 'easier access' or 'more and richer tools' are only relative. None of the current systems offers a truly integrated patient information flow. Psychological compensatory mechanisms may also be at play: one explanation of why users of alternative systems reported patients' strong opposition more frequently is that they are more attuned to perceptions that validate the choice of their practice clinical system.

Respondents perceived patient confusion and the anxiety created by media coverage as the most pronounced challenges of data sharing and improved coordination of care as the most likely benefit. Overall, they were most sceptical about benefits corresponding to hard outcomes and key priorities for the NHS (reduction of avoidable admissions, length of stay in hospital, and cost reduction). Robust evidence about the positive impact of data sharing, which is currently unavailable, appears more likely to persuade GPs and PMs of its benefits than powerful stories and visions. This hesitancy may, however, result in a self-fulfilling prophesy, since data sharing is likely to be effective only with a critical mass of committed users.

Both GPs and PMs reported high levels of discussing data sharing with patients, with fewer than 8% not raising the topic at all, suggesting that patients are given opportunities to express their preferences. Agreement to have one's data shared and surprise that this is not being done were the most frequently reported patient responses. Reports of strong objection were the rarest. This is in line with numerous studies and reports maintaining that most patients embrace data sharing for the purposes of direct patient care.[1,50-55] There was, however, a new and strong analytic direction suggested by our findings concerning the range of non-patient related factors associated with the frequency with which GPs and PMs discuss data sharing and the responses they receive. These factors included clinical IT system, professional role, GP clinical IT competence, and a respondent's perceptions of the challenges of data sharing. To a degree, they may stand for differences of context necessitating different decisions (e.g. the limited benefits of sharing through some clinical IT systems

may shift the cost-benefit ratio for some patients). Nevertheless, questions arise whether patients are enabled to make truly autonomous decisions about their data and the direction of decisions when these are better informed. We found, for instance, that respondents who self-rated their clinical IT system competence as highest were over three times more likely to report patient reservations. One possible interpretation is that patients find the added detail and realism around data sharing anxiety provoking and/ or disappointing.

Study limitations and strengths

The key limitations of the study arise from it being a self-report cross-sectional survey in a single locality, at a particular time period, and in the context of limited prior research. Standard limitations of survey methods are thus a pertinent consideration, such as concerns about cognitive biases and differences of reference points associated with self-reporting, impossible to eliminate ambiguity of wording, and limitations in identifying causal relationships and trajectories of change. For instance, anecdotal evidence from the broader study suggests that use of data sharing tools may have dropped after initial enthusiasm, indicating the importance of studying the uptake of project over time. In addition, as many of the parameters investigated have not been subject to similar research, the survey was a new tool building on very limited prior examples.

On the positive side, this is the first study exploring GP and PM's familiarity, engagement with and perceptions of patient data sharing in the UK and one with a high response rate. We also believe it to be the first study in the Health Information Exchange literature that demonstrates this level of entanglement of attitudes to data sharing of those who ask and those who are being asked about data sharing. Finally, these are findings about a rich and dynamic period in the early history of data sharing initiatives in the UK, providing helpful baseline information against which to evaluate future developments.

CONCLUSIONS

In our world of IT over-connection and health care over-fragmentation, patient data sharing is here to stay and improve. The scarcity of high quality research on data sharing is a serious concern against a background of both over-optimistic discourse and sensationalist exposure of risks, and of an exponentially growing number of projects. Robust research on the variety of models and outcomes of data sharing is needed so that healthcare professionals' and patients' perceptions and practices are more strongly grounded in evidence. Further research in the direction of this study, of exploring

users' perceptions of data sharing, is also crucial. When perceptions vary between "the best way to deliver patient care" and a "complete chaos and low clinical value", their capacity to drive different courses of action seems a given.

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