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

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ABSTRACT

Objective: In the UK, General Practitioners and Practice Managers are key to enabling health information exchange (typically referred to as ‘data sharing’). This study aimed to survey GPs and PMs for familiarity, engagement with and perceptions of patient data sharing.

Methods: Cross-sectional survey. All 107 general practices in England’s second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG. Descriptive statistics; hierarchical logistic regression; thematic analysis.

Results: 405 (64%) responses were received – from 338 (62%) GPs and 67 (71%) PMs. Familiarity and engagement were highest for local frail elderly and end of life care projects (> 76% had used). The greatest difference in use concerned the now suspended national *care.data* initiative: PMs had odds of reporting use 75 times higher than GP partners (95% CI 27–211). Patient confusion was the most pronounced challenge and improved coordination the most pronounced expected benefit. Frequency of discussions with patients varied with IT competence (OR 4.2 for most competent users relative to least, 95% CI 1.7–10.7) and clinical system (OR 0.3, 95% CI 0.1–0.5). Patient reservations were reported more frequently by respondents who rated their IT competence as highest (OR 3.3, 95% CI 1.5–7.6), perceived more data sharing challenges (OR for a 1-point increase in challenges perception score 3.4, 95% CI 2.1–5.6) and by PMs (relative to GP partners, OR 18.0, 95% CI 7.9–41.3).

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. Improved awareness of the impact of provider characteristics and attitudes on patients’ decisions about data sharing may enhance the equity and autonomy of those decisions.

1. Background

In a world of ubiquitous IT-connectivity and fragmented patient care, 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 1398 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 [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 are often disappointing [2,22,24,27,30–39]. 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 concerning “data sharing” (the preferred term for HIE locally): “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 key

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documents outlining its direction, such as the "Five Year Forward View" [40], "Personalised Health and Care Plan 2020" [41], "General Practice Forward View" [42], and is to be facilitated by the £4.2 billion investment in the digitalisation of the NHS [43]. It is also concurrent with a broader drive towards increasing service integration [44]. In the UK, general practice is the setting where the primary patient record is held and clinical IT use is best embedded. As of 2016, 98% of General Practitioners (GPs) are using an electronic medical record in daily practice routinely [45]. GP and Practice Manager (PM) engagement with data sharing projects is thus crucial to progress in the field. No similar survey addressing familiarity, engagement with and perceptions of data sharing amongst UK GPs and PMs has been published. To our knowledge, the only directly comparable study is of PMs and primary care providers in the state of Michigan, US [46].

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 [47]. Its core questions were:

- What are GPs' and PMs' self-reported levels of familiarity with and use of different data sharing tools?
- How do GPs and PMs perceive the benefits and challenges of patient data sharing?
- What are GPs' and PMs' perceptions of patients' attitudes to data sharing?
- What respondent characteristics are associated with 1–3 above?

The survey aimed to inform the work of the C & P Project team and other local decision makers involved in health IT projects by providing evidence on GPs' and PMs' knowledge, use and views on data sharing. By co-constituting the context of the C & P Project implementation, these were also seen as elements of mechanisms to be used in explaining the project outcomes within the broader research-evaluation study. Finally, the survey aimed to provide a snapshot of views on data sharing in UK general practice. While being a localised snapshot, it was developed with considerations for methodological transferability and the hope of motivating similar work in an area where expectations, promises, investments, efforts and vested interests are at exceptionally high levels, while rigorous research is scarce.

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

2. Methods

2.1. 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 (see GP version in Appendix 1, Supplementary file). Box 1 outlines the data sharing initiatives enquired about.

We investigated the relationship between responses and nine independent variables:

- practice clinical IT system
- GPs' perceived competence in using it
- Caldicott (information governance) Guardian status
- professional role
- years of experience
- gender
- Local Commissioning Group (LCGs are largely independent subunits of a Clinical Commissioning Group, there are eight LCGs in the Cambridgeshire & Peterborough CCG)
- time point of response (original survey, first or second reminder)
- 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.

2.2. 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, Supplementary file) 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.

2.3. 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 × £100. The final reminder included a brief note handwritten by MP.

2.4. 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%–10% of variables) were accounted for using multiple imputation by chained equations [48–50] in Stata v13.1 (StataCorp, College Station, TX). Imputed outcome variables were not used in analysis [51]. Binary variables were imputed using logistic regression, while continuous and ordinal variables were imputed using predictive mean matching [52]. Results from the ten imputed datasets were combined using Rubin's rules [48].

2.5. 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