

Qualitative investigation of the novel use of shopping loyalty card data in medical decision making

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ABSTRACT

This paper describes early results of a small qualitative study investigating the potential impact of shopping loyalty card data (SLCD) in the diagnostic pathway for ovarian cancer. There is early evidence that pharmaceutical products such as pain relief and medications for irritable bowel syndrome and bloating are bought by women to manage the early symptoms of ovarian cancer. Designed to be a formative interview study, two General Practitioners (GPs) in England were recruited to discuss the current pathway of ovarian cancer from a primary care perspective and to consider the value and impact of SLCD in medical decision making and its potential role in supporting improved referral times and patient outcomes. The findings indicate a potential role for SLCD, specifically in extending the diagnostic pathway to support earlier health information seeking and consultation with GPs. Communication with patients about this would need considering in regards to well established understanding about personal health behaviors and the wider system of primary and community care.

KEYWORDS: healthcare, medical decision making, shopping loyalty card data, diagnostic pathway, health information seeking

BACKGROUND

Within this world of ubiquitous digital technologies there are many sources of data now supplementing healthcare monitoring and decision making. On an individual level the data from fitness monitors/ watches and smartphones are most common and provide immediate feedback and real time information on physiological parameters. These data sets are now increasingly being utilised in a connected, positive way to support medical decision making by patients (service users) and healthcare professionals (HCPs). Beyond the use of devices which have been designed to capture health and wellbeing data there are other data sets which have the opportunity to provide a wealth of knowledge about a person's health, one such data set is that of shopping loyalty card data (SLCD).

Several academic centres are currently investigating the use and value of (SLCD). Set within a wider academic investigation exploring the concept of data donation for public benefit (Skatova & Goulding 2019), current research is exploring the potential role of SLCD in a number of clinical applications. The exploration of SLCD for early detection and prevention of certain conditions has implications for early diagnosis, health promotion and medical decision making on both a micro personal level and macro public health level.

This paper presents early scoping work to examine the use of SLCD within the specific use case of ovarian cancer referral in the UK. The enquiry delivers an initial qualitative exploration of GP perspectives on how SLCD could be utilised within the clinical pathway to improve referral times and patient outcomes. It provides early insight into the potential novel interactions of SLCD within the system of work, specifically how this new data set may disrupt current behaviours and decision making for women experiencing symptoms which could be indicative of ovarian cancer.

CASE STUDY BACKGROUND

Ovarian cancer survival rates in the UK are notoriously poor with less than half of those diagnosed being at an early stage of the disease. (Funston *et al* 2019). Symptom awareness and recognition (Barrett *et al* 2010), late-stage care seeking (Low *et al* 2013), late referrals and variation in initial assessment & investigation (Funston *et al* 2019) all contribute to high mortality rates.

Evidence suggests that symptom awareness may facilitate earlier attendance at GP consultations resulting in earlier referral and detection (Goff *et al* 2007), thus enabling more women to be diagnosed at a stage when the disease is possibly treatable (Funston *et al* 2022). As a result of the poor outcomes for this and other cancer pathways, there is increasing work to understand symptoms (Dilly *et al* 2020) and raise awareness of symptoms, encourage earlier consultation and for HCPs to proactively consider cancer within those consultations, all of which is articulated by the current goals of NHS England (2019) to expedite and increase referrals for suspected cancer (DHSC 2022).

Works by Olesun *et al* (2009) and more recently Williams *et al* (2019) provide insight into the complex and multiservice issues that may result in delays to diagnosis. Figure 1 is a high-level schema depicting how that occurs within a clinical pathway.

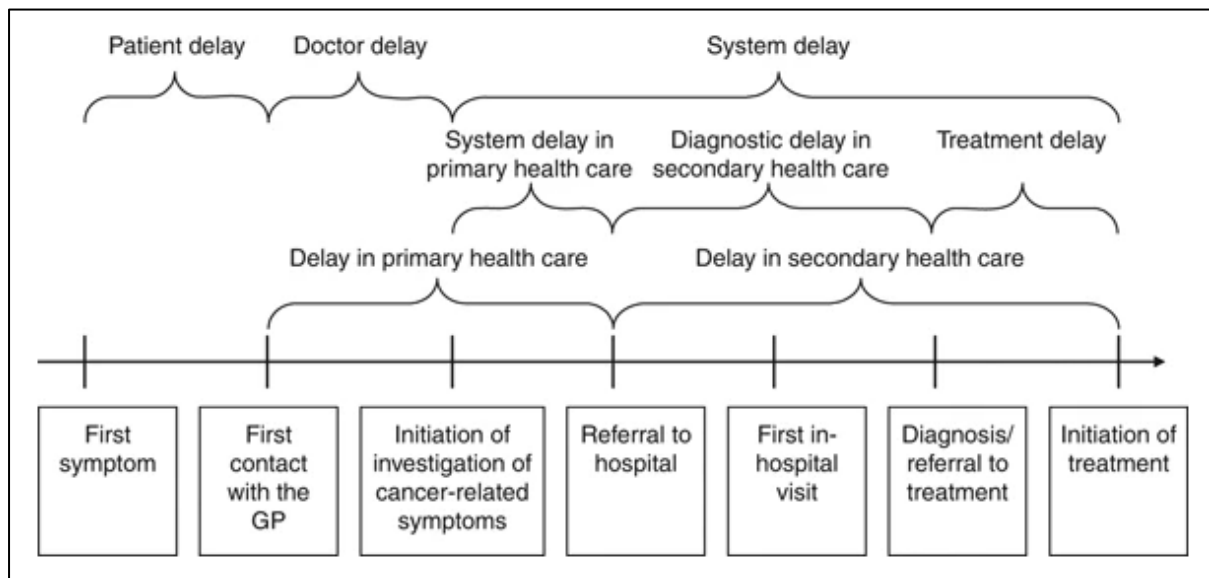


Figure 1. Delays in cancer diagnosis, The Aarhus Statement (Olesun *et al* 2009, Weller *et al* 2012)

The National Institute of Clinical Excellence (NICE) in the UK established evidenced based guidance for the recognition and initial management of ovarian cancer (NICE 2011), much of the detail of which has been replicated around the world in other healthcare industry guidance (Cancer Australia 2019). There is however suggestion that the guidelines might contribute to shortening intervals in secondary care but that they fail to consider the primary care component of the diagnostic pathway (Low *et al* 2013). Currently there are three main routes to diagnosis, with a recent study providing evidence that two thirds of cases are the result of referral by a patient's GP for outpatient investigations (although not necessarily to gynaecology), and nearly 20% of cases presenting as emergencies at A&E. A final cohort of 17% are identified via investigations within primary care itself (Barrett *et al* 2010). This demonstrates the key role of the GP in the pathway. However, despite in depth understanding of the routes to ovarian cancer diagnosis there are many barriers to service users' health information seeking behaviour and delays to referral within primary care. Recent work has looked into the important role of primary care nurses in this pathway, and their contribution to

early cancer diagnosis (Skrobanski *et al* 2019) something which up until recently has been overlooked.

SLCD

Current research is investigating the role of specific over the counter products and whether they could be indicative of early ovarian cancer symptom management. Dolan *et al* (in press) report on the early potential of machine learning and big data in understanding the relationships between frequency and duration of purchases of medications for pain relief, bloating, irritable bowel syndrome (IBS) and the risk of ovarian cancer. Other health conditions and medical diseases such as long COVID and diabetes are also being investigated using these methods (NLAB 2022). It is important that in parallel to these technical studies we begin to examine the potential value of this new data and insight and consider how it could be implemented in practice by all potential users.

METHODOLOGY

This is a small-scale scoping study and is designed to be a formative piece of research to inform a scaled-up investigation into the same topic. Literature review and in-depth review of existing clinical guidelines (NICE 2011) were utilized to develop an interview schedule. Two subject matter experts (SME's) were invited to remote interview. The SMEs were two female General Practitioners (GPs) both with over 15 years' experience of healthcare provision within the National Health Service (NHS), 12 each in primary care. Both work in the southeast of England but within different healthcare organizations within that region. Each interview took 75 minutes.

Interviews were designed to facilitate the SME's in talking through the current ovarian cancer pathway, describing their experiences of decision points and the patient role. They were asked to consider decisions identified in the process and any additional ones that are currently unseen or not well documented. This verbal walkthrough of the pathway was structured to elicit

- Information / data sets currently used
- Other cues and considerations
- Strategies for decision making
- Wider system challenges

Following the verbal 'walkthrough' of the pathway, the researcher introduced the concept of SLCD sets and the potential use of pre-diagnosis purchases to understand self-medication of early ovarian cancer symptoms as described by Dolan *et al* (in press). SMEs were then asked to consider the pathway and decision points but in relation to the potential use of SLCD as a supplementary data source.

RESULTS

The data captured from the interviews was thematically analyzed to gain a preliminary understanding of how SCLD might influence the pathway, patient choices and medical decision making associated with ovarian cancer primary care consultations and referral.

PATIENT BEHAVIOUR AND SEEKING OF HCP ADVICE

In support of the current literature there was acknowledgement that symptoms of ovarian cancer are difficult to identify as they are vague and often attributed to more common, but less high-risk conditions such as IBS, stress or general gastrointestinal complaints. This was discussed in relation to the current NHS strategy for improving cancer referrals and survival rates.

"From a GP perspective there is a massive agenda to increase early cancer detection. It comes from NHS England and is borne out of all referral pathways. So, there is this thing called positive predictive value of doing a referral, which is conversation rate of symptoms to cancer diagnosis. NHS England

want it to be about 3% which means for every 100 referrals you only pick up 3 cancers. But it's really difficult with ovarian cancer...it is so vague and for some it might be perceived as spending a lot of money on tests and referrals that come to nothing. The good thing about the new strategy is that it tries to remove the old view that we (GPs) had to be conservative when considering cancer in our investigations and referrals."

Considering the established pathway, both SME's felt that there was inadequate awareness of ovarian cancer symptoms in the general public and that more should be done to encourage women to seek medical advice when experiencing symptoms. It was believed that any additional mechanisms or data sets to support that awareness would be a good thing, especially in light of workload issues experienced in primary care. It was also discussed how, from the professional side there is variation in the awareness of and willingness to consider cancer referrals at an early stage. They expressed the view that recent changes to national cancer strategies (DHSC 2022) will help this but that there is a time lag between change in guidance/ strategy and change in clinical practice.

"Once you walk through the door at the GP there shouldn't be barrier to you being investigated for cancer. There's an easy blood test and an easy scan, they are readily available without much of a waiting list. Certainly, in my area that is the case. If someone also told me, they had bloating and abdominal pain they would get those tests."

There was consensus from both interviewees that there is variation in when and how women seek health information and advice and that improving this is a key factor in reducing time delays to diagnosis as depicted in Figure 1. Existing blood tests and scans that are used for ovarian cancer referral are relatively cheap and so it was felt that early utilization of these should be a priority for patients who are in consultation with GPs for any of the cancer symptoms.

"We are all knackered, we are all over worked. And sometimes we will miss things.....more information, if it can be made available but not a burden, well that could be good. But also, if there is something that helps them (patients) get through the door then that can only be a good thing."

The SME's considered at length the reasons why women experiencing symptoms (even if unaware of the potential risk of ovarian cancer) may not seek medical help. They explicitly referenced the five established triggers that are understood to lead individuals to present at a doctor's appointments (Zola 1973)

- a) Perceived interference with vocational or physical activity.
- b) Perceived interference with social or personal relationships.
- c) Occurrence of an interpersonal crisis.
- d) Temporizing – "if not better by Monday", or "just two more nosebleeds".
- e) Sanctioning pressure from family and friends.

"It can be a battle to get some patients to see us" (relating to Zola's triggers) "If we can bring the pharmacist into that conversation....and try to get women in earlier it could make a huge difference to outcomes. This is the problem with ovarian cancer, the symptoms are so vague, and it catches you out often with those who don't have strong family history or very clear indications"

Braunack & Avery (2009) pose how individuals have a tendency to attribute symptoms to other causes and may not be cognizant of their relation to other conditions which might have more of an influence on the Zola's triggers. There was suggestion within the interviews that 'making the link' and highlighting how long-term experience of those symptoms could relate to the triggers as a communication could be the way in which to utilize the SLCD to alter patient behavior.

“So, if well, the shopping data picked up a pattern and that it was communicated in a way that might influence those triggers then it might well help patients think about coming (to the GP) earlier.”

The work by Leydon *et al* (2009) investigated health behaviors related to uterine conditions and in this study prospective patients followed a pattern of self-care first: they identified that they had a problem; then they attempted to address it. Only when the symptoms began to interfere significantly with everyday life did they finally make a visit to the doctor. The interviews established that this kind of pattern was a reality for women with ovarian cancer symptoms and that more needed to be done to overcome the barriers to health information seeking & attendance.

The opportunity for SLCD to contribute to women deciding to make and attend a GP appointment was viewed positively, but with the acknowledgement that not all women would engage with the data.

“Certain people might not take any notice, but that is like anything. But there are those who, if they received some information or maybe a bit like a public service announcement associated with their personal buying patterns, might then consider attending a GP appointment sooner. Anyone who gets through the door earlier as a consequence would be a win for the health service”.

There is much still to be understood about the impact that SLCD might afford women in their decisions to seek advice from healthcare professionals about ongoing symptoms. However, there is early indication that any data tool that might support earlier attendance by women with those symptoms would be a positive thing in terms of referral rates, successful and earlier diagnosis, patient outcomes and also health economics in terms of treatment interventions.

PATHWAY MODIFICATIONS DUE TO IMPLEMENTATION OF SLCD

The information provided by the SME's indicate that the introduction of SLCD could support improvement of the ovarian cancer diagnosis pathway, extending its remit into community care beyond that of current primary care providers. Figure 1 depicts a breakdown of the typical stages associated with cancer diagnosis, but importantly shows where delays are incurred in that pathway. Whilst there is undoubtedly action that needs to be taken to prevent delays within primary and secondary care systems, a significant theme to come out of the two interviews was the need to bring forward and minimize delays at the point of accessing the first GP appointment. Both SMEs independently suggested how SCLD could be utilized by pharmacists to support women in decision making about seeking health advice and consultation.

“For frequent use - I find pharmacists and pharmacy technicians, they are so good at directing patients.....quite often I have people say to me 'I showed this to a pharmacist, and they weren't happy, so they sent me to you”.

It was considered that if SLCD did support earlier identification of ovarian cancer symptoms then this would have most value in the community, to encourage women to access health advice earlier.

“So, if a pharmacist did spot a pattern, if say they did see something in the Boots advantage card and there was a system where it would raise an alert to say this patient has bought X number of pain relief, x no of cystitis medication and also X number of Buscopan.... Maybe have a discussion with them. Then that could be really brilliant, also because patients really trust their pharmacists”

Discussion around automated information provision, communication and language were touched upon, but it was felt that much more work would be required on the user interaction with the

information and how it might be presented or delivered to ensure engagement and possible adherence with guidance provided.

“In regard to patient decision making and the spread of over the counter and off the shelf products... if there was opportunity for patients to recognize their frequency of purchase, well that might make them really think about their symptoms and what they are self-medicating. But it’s how you are communicating that...it might generate a conversation or even a leaflet. You are buying x, y, and this could be chronic constipation, etc. but it could be something else. It might be useful for you to speak to a GP to just check it out”.

Further, it was believed that there was interesting work to be carried out to explore if and how this vital information could be provided to women, both with and without the involvement of a pharmacist or community nurse.

“If we can bring the pharmacist into that conversation or even GP nurses....well they are other professionals trying to support women even before they have spoken to a GP, it might make for earlier dialogue or real consideration of the symptoms...so that could lead to them taking action at a point in time when without that data it might not be possible. You’d also have to think about people who don’t want to or might not use those services and how to engage women who don’t have much contact and just self-manage for long periods of time.”

Variation in service user behavior and understanding types of people was considered a crucial factor in whether or not SLCD could be used in a way that might have positive impact on the early stages of the pathway. This was mentioned in relation to several variables, health anxiety, use of NHS resources, the parameters relating to the Zola’s triggers and the relative importance placed on those by individuals.

“Sometimes you get a patient who thinks they are a superhero and sometimes you get ones who just can’t face any investigation as they are so anxious. Communication of that data would have to be very sensitively done. Maybe.... flag up in app and then follow up leaflet with suggestion to speak to doctor.”

Finally, the interviews reflected on the role of SLCD on their own medical decision making, specifically in terms of ‘watch and wait’ practices, decisions to undertake accessible tests in primary care and also timely, early referral decisions. It was expressed that most GPs should be thinking of cancer and not prolonging care without considering cancer as an underlying cause of symptoms over a period of time. However as mentioned, the acknowledgement of variation in practice was considered a potential contributor to delayed referral and so the SLCD could help to overcome some barriers to referral by adding additional evidence to the decision-making process.

“Bring any evidence that helps trigger that thought process earlier, whether it be because of experience in the job, people thinking about the cost of tests or even being over worked and what that does to how we think about what to do with patients...well that (SLCD) could be beneficial. Anything that brings attention to it, it can only be useful to them (the patients) and us.”

“Certain tests we steer away from as they are non-specific and not as helpful but the CA12 (blood test) is really good, good information and helps. If the shopping data could help add weight to the evidence of the symptoms, how long they’ve been going on for etc. then I think for most GPs it would help them decide to do that test, and maybe a scan, earlier”.

DISCUSSION

This formative work is only small scale and very limited in the scope of its enquiry. However, within the interviews conducted some interesting perspectives have been raised that have opened up the dialogue about the implementation of SLCD into primary care practices.

Whilst limited in its applicability it is worth noting that excitement was expressed by the SMEs about the potential value of this kind of data being utilized within the diagnostic pathway and also in regards of empowering women to make better, earlier decisions if they are experiencing long symptoms which might be associated with ovarian cancer. It might be that the novelty of this concept initially prompted largely positive responses from the interviewees. They acknowledged the issue of workload on multiple occasions and there may be bias associated with any proposed intervention that has the potential to improve patient outcomes with minimal addition to workload. This in and of itself needs to be investigated to really understand the integration of new data sets into clinical practice and understand current Work as Done and what might change look like with the introduction of SLCD.

One point to raise specifically is the extension of the diagnostic clinical pathway into the community. Figure 2 represents how the data from these interviews has made suggestion of reduced delays associated with the patient behavior and medical decision making, doctor decision making associated with tests and referral times.

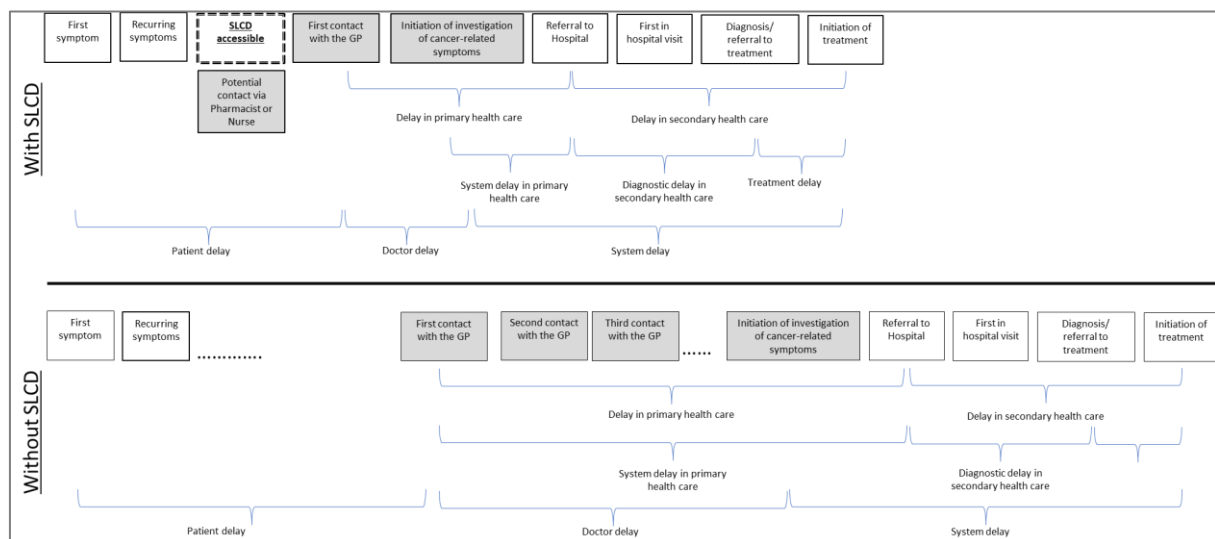


Figure 2. Comparison perceived diagnostic pathway delays with and without SLCD

It is evident from this scoping qualitative enquiry that according to GP's there may be a role for SLCD to provide better care of women experiencing symptoms which may be associated with ovarian cancer. It is evident that there are many factors that impact health information seeking behavior and there is

- a) a potential role for SLCD to add understanding about an individual's personal health which could contribute to earlier presentation at a doctor's appointment.
- b) potential for other HCPs to be involved in the use of SLCD and bring them into the pathway to better support women and GPs in encouraging early presentation.
- c) opportunity for more evidence to support more timely tests and referrals for women presenting with those symptoms.

These findings will be crucial in forming the design of subsequent would be used to design future research enquiries into how we examine the use and value of this data set for ovarian cancer and other conditions. There is opportunity for human factors models such as the Systems Engineering Initiative for Patient Safety 2.0 (SEIPS 2.0) model (Holden *et al* 2013) to provide a framework for

examining the human factors challenges and considerations of service users and HCPs in utilizing this data set within their care pathways and service delivery.

Future research into this topic will look to examine the system of work and requirements of HCPs in further depth, involving not only GPs but other relevant stakeholders, some of whom have been mentioned by the interviewees (pharmacists, community nurses) but also others who may not be clinically trained but who would need to integrate the data set into existing system and service infrastructure. Patient requirements and perspectives are vital to the success of this, and it would be pertinent to examine those within and between different medical conditions so that the potential implementation of SLCD is not only understood in its application to ovarian cancer.

CONCLUSIONS

This paper provides an early analysis of the use of shopping loyalty card data (SLCD) in work and interactions associated with medical decision making within the diagnostic pathway for ovarian cancer. There is a universal need to improve cancer detection rates and the UK has prioritised this as a strategic goal for the NHS. Novel data sets such as SLCD have the potential to disrupt current pathways and may offer additional information to support health information seeking behaviours by patients and more evidence to GPs in their clinical decisions. This study provides early evidence to suggest that there could be a role for SLCD in primary care and that further work is required to understand these interactions and the potential value of SLCD more broadly in health and care service delivery.

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