

Assessing self-management behaviours of ovarian cancer patients before their diagnosis using commercial data: a proof of concept study
James M Flanagan¹; Hanna Skrobanski^{2,3}; Xin Shi^{4,5}; Yasemin Hirst²

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Project Background

The ten-year survival rate for epithelial ovarian cancer (EOC) is only 35% in the UK and is dramatically different for stage 1 disease (90%) compared with stage 3-4 (5-15%). Survival in the UK lags behind Europe; this is attributed partly to a delay in diagnosis². Earlier detection of low-volume disease or earlier stage ovarian cancer will save lives³.

EOC is a heterogeneous disease with different histological subtypes that show strikingly different molecular⁴ and mutational profiles^{5,6}. With the Ovarian Cancer Association Consortium (OCAC), we have identified 34 common genetic polymorphisms contributing to polygenic risk⁷⁻¹⁰. Epidemiological risk factors provide a predictive model with a modest discriminatory power (AUC=0.65), improved slightly with polygenic risk (AUC=0.66)¹¹, and this model has been proposed to improve EOC detection with risk stratified screening¹².

common symptoms associated with EOC are increased abdominal size, pelvic pain, abdominal pain and bloating, feeling full quickly and difficulty eating^{13,14}. The major reasons for not presenting to the GP with symptoms such as these are "not wanting to waste the GP's time"¹⁵ and normalisation of these symptoms¹⁶. The persistence of a symptom, social influence and awareness encourage help-seeking behaviours in primary care¹⁷. However, few believe that their symptom(s) might be a sign of cancer¹⁸. Consequently, people might choose to self-manage their symptoms by using over-the-counter medication, and to seek advice from other sources, (pharmacists, family, internet), rather than a primary care physician.

In 2016-2017, funded by a CRUK Innovation grant focusing on "Harnessing Technology", Dr James Flanagan and colleagues investigated the feasibility of monitoring self-management behaviours of ovarian cancer patients prior to diagnosis. For this we applied to access a high street retailer's loyalty card data through the Consumer Data Research Centre (CDRC) secure data service. Acquiring this data allowed us to explore public acceptability of commercial and health data linkages to inform how future large scale studies could be conducted [1]. Loyalty card data has been previously used to investigate adherence to cardiovascular medications¹⁹, to incentivise a healthy diet^{20,21} and to trial nutritional profile labelling²². However, it has not been previously used for cancer.

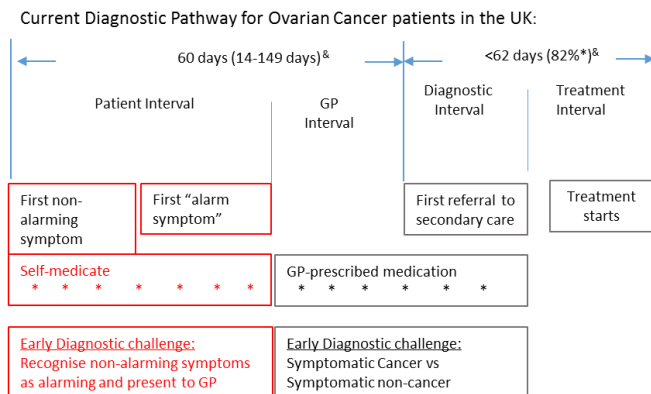


Figure 1. Current diagnostic pathway for ovarian cancer patients in the UK. The patient interval (the period between first recognising alarm symptoms and presenting in primary care) plus the GP interval (until referral to secondary care) is on average 60 days (25th-90th centile 14-149 days) in the UK for ovarian cancer patients (& Lyratzopoulos G, et al. Br J Cancer. 2015). This study aims to reduce the time it takes for patients to recognise non-alarming symptoms as potential cancer related symptoms to reduce the patient interval by identifying self-medicating purchases indicative of cancer related symptoms.

EOC usually presents with vague and non-alarming symptoms; as a result most women are diagnosed late when the cancer has already spread and the prognosis is poor. The most

Hypothesis Generating

In our pilot study looking at self-management behaviours, 19/70 (27%) ovarian cancer patients invited consented to the study and we observed higher purchases of pain and indigestion medication among ovarian cancer patients compared to a healthy control. We observed potentially relevant purchases up to 12 months prior to diagnosis. These consumer data, therefore, provide an exciting opportunity to investigate a novel method for earlier detection.

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Focus Groups

Using four focus groups (n=29, aged 25-66) we aimed to understand the attitudes towards commercial and health data linkage for the surveillance of potential cancer symptoms. In general, people found cancer symptom surveillance using commercial and health data linkage as a futuristic and an exciting idea; however, wanted researchers to consider the data and the outcomes with caution. Participants were willing to consent to data linkages if transparency, security and accountability are assured.

The research shows that for convenience outlets, the exterior atmosphere and micro location factors act as more important roles on consumer patronage than they do for larger store formats. Especially for the outlets located in major cities, customers would shop for their instant needs (like newspaper, meal for today, or refreshment). Therefore a convenient location and eye-catching outlook are important to attract consumers to visit the store.

Conclusions and value of the research

We held an advisory group meeting on 31st October 2017 with ovarian cancer patient advocates, academics, clinicians, representatives from the ESRC Consumer Data Research Centre (CDRC, UCL), charities (CRUK and Ovarian Cancer Action) and three high street retailers to evaluate our findings and discuss future research plans. The meeting highlighted the priority of linking these novel datasets to understand ovarian cancer symptoms as well as the importance of a large scale prospective study.

In conclusion, cancer symptom surveillance using commercial data is feasible and also acceptable to the general public. To test efficacy of cancer surveillance using commercial data, larger studies are needed with links to the individual electronic health records.

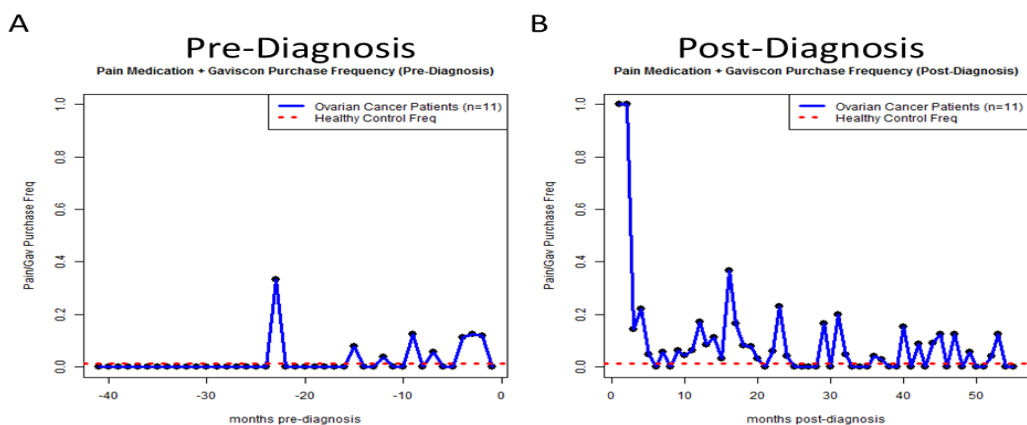


Figure 2. Purchase Proportions of Pain and Indigestion Medication stratified into pre- and post-ovarian cancer diagnosis. We obtained data from 11 ovarian cancer patients and one healthy control, including 1118 purchases from April 2013 to July 2017. For each month the total purchases for each category were normalised by summing each category and dividing by the number of all purchases in that month for the ovarian cancer patients (blue line) compared with the average monthly purchase proportion for that category in the healthy control subject (red dotted line). Purchases are shown for (A) pre-diagnostic time compared with (B) post-diagnostic time.

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Footnotes

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Assessing self-management behaviours of ovarian cancer patients before their diagnosis using commercial data: a proof of concept study
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