Guest editorial

Innovative methods in health information behaviour research
Introduction

Regardless of numerous attempts to expand studies in terms of the scope of diseases, disease phases and treatment contexts, such as hospitals vs home-care, frustrations about unmet information needs prevail, especially amongst patients and caregivers. Ongoing attempts to improve patient communication and education and innovative methods of sharing information are also not fully succeeding in addressing information needs and preferences (Johnson and Case, 2012). For example, Davies *et al.* (2010, p. e861) show the impact of a lack of information on the quality of life of a Spanish-speaking mother of a child in palliative care. During a month's stay, she washed in her child's bathroom sink because she received no orientation regarding available facilities. She feared asking questions. "I didn't know. I thought if I asked someone they would answer me in English, and I wouldn't be able to communicate". Numerous similar examples can be found in the literature (Fourie, 2012; Fourie and Nesset, 2017). Not only patients and their caregivers, but health professionals are also in dire need of information that suits their needs (Johnson and Case, 2012). Globally millions of people are affected by diseases and sporadic epidemic outbursts (World Health Organization, 2019) – the numbers of people affected, the challenges faced and the fact that health information seeking research are now also focussing on the ongoing need to stay healthy and to collect information on personal activities such as tracking, and necessitate the need to extend how we study health information seeking. Against this background, the purpose of this special issue was to turn to innovative research methods as one approach to deepen understanding of health information behaviour.

For purposes of this introduction, information behaviour refers to all information-related activities and encounters, including information seeking, information searching, browsing, recognising and expressing information needs, information encountering, information avoidance and information use (Fourie and Julien, 2014 – acknowledging definitions by well-known researchers such as Donald Case, Reijo Savolainen and Tom Wilson). This interpretation can also allow for information practice. According to Savolainen (2007, p. 127), the major difference between the two concepts is that in the discourse on information behaviour, the "dealing with information" is primarily seen to be triggered by needs and motives, while the discourse on information practice accentuates the continuity and habitualisation of activities affected and shaped by social and cultural factors. Both "information behaviour" and "information practice" are used in the papers included in this special issue.

In the Call for Papers, we stated that health information behaviour research can benefit from studies using a range of more innovative methods, including participatory methods, visual research methods, metaphor identification, methods focussing on embodiment, discursive research methods such as narratives and traditional storytelling, autoethnography, and agile research methodology. Although these were not all covered in the submissions, contributors to this issue brought other valuable methods to our attention. In the call, we highlighted two core issues: a critical assessment of the method, and its particular value for the group studied. Eight contributions addressing innovative methods used in health information behaviour and practice research are included in this special issue.

The contributions bring value by highlighting the:

- diversity of groups that need to be studied: patients, caregivers, physicians (and other health professionals) and institutional perspectives;

- need for deeper exploration of both quantitative and qualitative methods and the need for supplementary methods in data collection;

- need to build on prior work and the need for testing existing theories, insights and instruments in order to move forward;

- awareness that useful methods such as photography, text summarisation or key concepts such as "serendipity" and "intergenerational" have often existed for some time without being explored in the realm of health information behaviour and sometimes not even in Information Science;

- fact that valuable methods are reported, but not adopted by information behaviour researchers; this will be illustrated in the references we note for each method in addition to the references listed by the authors (these references will hopefully stimulate further innovation in health information behaviour research);

- valuable body of available literature and the need to explore key works beyond the discipline of Information Science and information behaviour research; and

- need to look wider than the immediate body of repeatedly cited literature for different methods, theories, participatory groups and data collection methods.

What becomes clear from the authors' citations was that none of the methods, or in one case the methodology, are really new. They have all been noted in the literature over several decades, for example, institutional ethnography (Townsend, 1992; Walby, 2007), and photography (preceding photo-elicitation) (Collier, 1957). A title search in two key databases relevant to health information behaviour, namely, Library and Information Science Abstracts and Medline (medical database), and for one paper also Web of Science (all databases) confirmed that uptake of these methods in health information behaviour research is, however, very limited. This confirms the value of this special issue. We expect that our extended list of references, in addition to the work cited by the authors, can further stimulate the use of innovative methods and contexts, and can extend the work reported here.

We are grateful to all submitting authors and to all the reviewers who supported us with their careful reviews and challenging questions. We also want to express our gratitude to Professor Dirk Lewandowski, editor in chief of *Aslib Journal of Information Management*, for facilitating this special publication on the use of innovative methods in health information behaviour.

Contributions and themes covered
Each contribution is briefly contextualised in the following paragraphs, before adding our comments, and references to show the uptake of the method in information behaviour research, Information Science and Health Science.

Institutional ethnography
Nicole Dalmer reports on the use of institutional ethnography as a method of inquiry that brings attention to people's everyday work while simultaneously highlighting broader sites of administration and governance that may be organising that work. Considering the increasing burden on informal caregivers and local community services to support patients diagnosed with life-threatening and life-limiting diseases (Fourie, 2012), this paper is welcomed for raising awareness about the impact that infrastructures and policies might have on many issues that can impact on information behaviour, e.g. informing patients, information exchange and work practices of multi-disciplinary teams (Caspar *et al.*, 2016; Ion, 2019; Quinlan, 2009; Reid *et al.*, 2018). The paper also confirms the

value of the key work of Dorothy Smith (2005) (also stressed in Kearney *et al.*, 2018), and the importance of moving beyond interests in individuals only. Institutional ethnography has been used in various healthcare contexts, including nursing and mental health (Knyahnytska, 2014; Rankin, 2003; Walby, 2007), but with very limited uptake in Information Science; Ocepek (2018) and Pilerot (2016) note it in their work on, respectively, everyday life information behaviour and evidence-based practice and social welfare service, and Dalmer notes a few other works, in addition to her own, that use the method. In exploring a wider spectrum of disease and healthcare contexts, health information behaviour researchers might also consider combining institutional ethnography with methods such as community-based and participatory approaches (Nichols *et al.*, 2017) and autoethnography (Taber, 2010). Institutional ethnography can be approached as a method of empowerment (Boucher, 2018).

Enhanced participant-driven photo-elicitation

Yuanyuan Feng reports the use of enhanced participant-driven photo-elicitation for an everyday life health information behaviour study using tracking devices. An interesting addition to the paper is the reference to personal information management (PIM) activities. Although PIM is well-known in the Information Science literature (e.g. Lansdale, 1988), it is only now getting a more prominent focus (Darling and Tilton-Weaver, 2019). Although photography and photo-elicitation are noted in the medical literature (e.g. Clark, 1991; Clark-Ibáñez, 2004) there has been limited uptake in information behaviour research. Researchers might consider photo-elicitation as method for child participants (Poku *et al.*, 2019), challenging diseases and disease disorders such as autism spectrum disorder (Danker *et al.*, 2017), vulnerable groups (Copes *et al.*, 2018), and to understand cultural practices (Ndione and Remy, 2018). From the medical literature topics of interest to information behaviour might be contexts of artificial nutrition and hydration for people in a permanent vegetative state (Cretin *et al.*, 2017), lived experiences with pain (Rolbiecki *et al.*, 2019), end-of-life care (Hajradinovic *et al.*, 2018) and people affected by repeated self-harm (Edmondson *et al.*, 2018).

Eye tracking

Jacek Gwizdka, Yan Zhang and Andrew Dillon explain the value of eye tracking to study consumer online health information search behaviour. The paper introduces a unique method for information research in general and online health information search in particular. It also provides readers with an awareness of how to capture and interpret such data. Although eye tracking is not a new research method, use in health information behaviour has been limited. The paper by Gwizdka, Zhang and Dillon is thus a welcome addition to pave the way for further research in health information seeking and use. Related work from the medical literature includes studies on searching images from scans: Drew *et al.* (2017), Jiang *et al.* (2017), Mello-Thoms *et al.* (2006), Van der Gijp *et al.* (2017) and Veneri *et al.* (2012). These types of studies point to potential information behaviour studies with health professionals or marginalised groups such as individuals with Down syndrome and autism spectrum disorder (Eraslan *et al.*, 2019). Other contexts for eye-tracking studies include emotional attention and encoding in the retrieval of ambiguous information (Everaert and Koster, 2015); web-based breast cancer decision making (Shaffer *et al.*, 2013); specific types of searching such as for vaccination (Kessler and Zillich, 2019); and the effects of search interfaces and internet-specific epistemic beliefs on source evaluations (Kammerer and Gerjets, 2012). In Information Science, eye tracking has been acknowledged for some time but with no evidence of prominent uptake (Lund, 2016; Muntinga and Taylor, 2018; Schultheiß *et al.*, 2018).

Application of the Applied Information Flow-Serendipitous Knowledge Discovery (IF-SKD) model
Mark Hopkins and Oksana Zavalina share findings from their work on physicians and Serendipitous Knowledge Discovery (SKD) of health information, where they tested the Applied IF-SKD model. The value of this paper further lies in the fact that they raise awareness of extended research on serendipity – a concept examined in the Information Science literature for many years (e.g. Bernier, 1960), and for the value of building on the work and instruments of other researchers (McCay-Peet *et al.*, 2015). Although serendipity has featured in the literature of both Information Science and Health Science, with renewed interest (Forrester, 2019; Shneiderman, 2019), it is not often a focus in studies of information behaviour. The health literature reveals many potential subjects for health information behaviour researchers, and for further assessment of the instrument, e.g., serendipity in drug discoveries, diseases and dysfunctions (De Clercq, 2015; Goldstein *et al.*, 2019; Michelucci, 2019).

Infodemiology approach to study temporal patterns and variations
Utilising the infodemiology approach to study temporal patterns and variations, Jonas Tana, Emil Eirola and Kristina Eriksson-Backa report on rhythmicity of health information behaviour. Although there are papers reporting the use of infodemiology in health-related information behaviour from medical perspectives, e.g., Brigo *et al.* (2018) reporting on online information seeking related to the Italian Wikipedia and epilepsy, Hill *et al.* (2011) on internet searches for H1N1 influenza, Zhang *et al.* (2013) on the use of twitter to monitor physical activity and Blomberg *et al.* (2019) on using a Facebook forum to cope with narcolepsy after pandemrix vaccination, there is very limited mention of infodemiology in the Information Science literature and hardly any in information behaviour research. Although a focus on the temporal is also not new in information behaviour research (Amitay *et al.*, 2004; Combi and Shahar, 1997; Kimia and Ahmadi, 2018; Rahmi *et al.*, 2019; Savolainen, 2018), it is certainly a novel addition when combined with infodemiology, and is an approach that could trigger interesting research.

Posting analysis in virtual health communities – sense-making and sense(s) of normalcy
Sharon Naveh and Jenny Bronstein report on an analysis of pregnant diabetic women's postings in virtual health communities. The novelty of the paper lies in their application of Dervin's sense-making methodology and determining sense(s) of normalcy; this brings an interesting perspective to information seeking studies. Both the literature from a medical/ health perspective and the literature in Information Science and especially information behaviour show limited work related to senses of normalcy or normality. Exceptions are Petriček *et al.*'s (2017) reporting perceived needs for attaining a "new normality" after surviving myocardial infarction, Werner and Malterud's (2016) reporting on children of parents with alcohol problems, McKevitt *et al.* (2019) on parents' experiences of childhood stroke, and Panteli and Marder (2017) on constructing and enacting normality online across generations. Two important studies that are more pertinent to studies of information behaviour are Taylor *et al.*'s (2013) reporting on situation normality and the shape of search: the effects of time delays and information presentation on search behaviour, and Genuis and Bronstein's (2017) reporting on looking for "normal", and sense making in the context of health disruption. There are many situations in healthcare that can benefit from the methodology applied by Naveh and Bronstein, especially situations in progress, e.g., caregiving experiences with people living with chronic pain, sexuality transitions, mental disorders such as schizophrenia, memory loss and end-of-life, and grief and bereavement.

Intergenerational participatory and community participatory design
Charles Senteio describes the design of a health information and technological educational intervention based on intergenerational transfer that intends to promote health information sharing and technology use for older African-Americans with diabetes. There is very limited evidence of the use of the concepts "community-based participatory" and "transgenerational" in health science literature (e.g. Agee, 2000; Barrantes Cáceres and Cozzubo Chaparro, 2019). There is some use of these concepts in Information Science, but not in combination or in relation to information behaviour. Examples of papers in Information Science reporting on intergenerational research include Bratianu and Leon (2015), Harvey (2012), Henner (2009) and Large *et al.* (2006). Lin *et al.* (2019) is one of few examples reporting on a community-based participatory health literacy programme for older adults – but does not include the intergenerational element. Rubin (1999) published a biographical paper on intergenerational library programmes.

Text summarisation of social media messages
Yi-Hung Liu, Xiaolong Song and Sheng-Fong Chen explore the value of text summarisation in finding health advice from health social media. Similar to the other methods discussed in this special issue, text summarisation and sentiment analysis are not new methods. In the Health and Information Science literature, there are papers reporting surveys and reviews on text summarisation (Gambhir and Gupta, 2017; Lloret and Palomar, 2012) and various applications (Wang and Yang, 2006). Only a few studies focussed on biomedical literature (e.g. Reeve *et al.*, 2007a, b; Scott *et al.*, 2013), but not in the context explained by Song. It is likely that effective text summarisation of health social media messages can also support patient decision making and coping – a topic requiring further investigation.

Conclusion
The biggest potential for future research lies in appropriate combinations of different methods of data collection and ongoing expansion of the disease conditions, participation groups and contexts we study. Methods that can complement each other, that can extend the scope of the types of data collected beyond words and numbers, and that can extend understanding beyond individuals and groups to institutions, governments, policymakers and educators are especially important. Future research also requires exploration with methods of data collection that are less intrusive and place less demand on participants' time. Understanding of the value of such methods and their use across disciplines can benefit from rigorous systematic literature reviews, meta-analysis and content analysis (Lloret and Palomar, 2012; Lund, 2016), and extending the disciplinary range of the literature used to inform information behaviour scholarship. A next step would be to consider innovative methods of analysis and triangulation. Five ways of doing qualitative analysis: phenomenological psychology, grounded theory, discourse analysis, narrative research and intuitive inquiry, where the authors analyse the same experience from different perspectives, set a good example: "In contrast to traditional received methodological hierarchy, on one hand, and an unprincipled relativism, on the other, a well-grounded, evidence-based science utilizing multiple approaches is possible and desirable. Different approaches can relate to each other not as strangers or rival but as respectful friends" (Wertz *et al.*, 2011, p. 399).

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Further reading

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