



Knowledge is power?

With access to an unprecedented amount of healthcare information, how do healthcare professionals and the public sort fact from fiction?

HEALTH AND PATIENT information: in the UK we have plenty of it. The public has free access to vast amounts of information about health conditions, including the NHS's own patient information website, NHS.uk, and the College's own patient information leaflets. Healthcare professionals also have access to clinical guidance including the RCOG's Green-top Guidelines and datasets such as Hospital Episodes Statistics (HES) – recognised internationally as world-class data – to help inform their clinical care.

Quantity of information certainly isn't an issue. There is a lot of good quality, evidence-based information (although a lot of it is complex and hard to engage with), but there is also a vast amount of inaccurate or, at best, misleading information out there. Interpretation and use of information lag behind the quantity that is available. For both patients and

healthcare professionals, being able to understand and use information and data is key to improving patients' experiences and outcomes.

'Dr Google' has a lot to answer for: the impulse that makes people type their symptoms into a search engine only to then become convinced from the search results that they're suffering from a rare disease. Joking aside, it masks a wider problem.

“A woman thought her ‘positive’ cancer diagnosis was a good thing and couldn’t understand why she wasn’t getting better”

According to Health Literacy UK, a special interest group of the Society for Academic Primary Care, levels of functional health literacy are low (at least in England). “Health information in current circulation is written at too complex a level for 43% of working-age adults (16-65 years),” the organisation states on its website. “Research from the USA and Europe shows people with low health literacy are more likely to have a long-term health condition and this is more likely to limit their activities.”

Patient-facing information

Jonathan Berry, personalisation and control specialist in NHS England's Person Centred Care Team, has blogged about the impact of this on patients in England. nhs.uk/blog. He relates the stories of a woman who thought her 'positive' cancer diagnosis was a good thing and couldn't understand why she wasn't getting better, and a group of women who didn't know where their cervix was. Most obstetricians

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Internet information sources

We invited members of our Women's Voices Involvement Panel to tell us (anonymously) on Facebook about their experiences of trying to find health information online. Here's a selection of their comments

"I feel the internet is here to stay so instead of resisting it, doctors need to realise there are some really good bits and focus on them and pointing patients towards them, instead of saying 'don't go on Google' – how unempowering to a patient."

"The worst sources are random pages from googling. Good sources are RCOG patient info leaflets, RCOG guidelines, NICE guidelines."

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"RCOG is working with NHS Digital to push NHS.uk as one of the go-to places for information on women's health in the UK"

and gynaecologists have similar examples.

Interestingly, most of Jonathan Berry's examples are women. For women – who access healthcare more frequently and routinely than men – a lack of health literacy can have particularly serious consequences. And this is why education and information are key strands of the RCOG's women's health strategy, due to launch in October 2019.

Improving health literacy at an early age is one aspect of the education challenge. "If you get it right there then it makes a really big difference to women as they

go through their lives," explains Jenny Priest, the RCOG's Director of Policy and Public Affairs. "We want girls at school to be learning about menopause – rather than women getting into their 40s and people saying to them 'do you feel a bit perimenopausal?' and them thinking 'I don't know, do I?'"

Signposting reliable information

This could be tackled through changes to sex and relationship education in schools, and is an example of where a lack of information and education in the past is being addressed. However, what about the opposite problem: helping women to navigate the vast quantities of health information – some good, some bad and some dangerously misleading – freely available on the internet?

"There are some specific issues around information for women who are moving past adolescence, into their 20s and 30s," says Jenny. "The feedback we've had from our Women's Network is that there's almost too much information. When you google something, so much comes up from overseas, particularly the USA. It might be fine but there's no way of being sure."

Finding a way to 'kitemark' high quality health information on the internet that is based on evidence would be the ideal, but there isn't the technology or resource to do that. The College is working with NHS Digital via the Women's Health Taskforce, which is co-chaired by Lesley Regan, to push NHS.uk, already an excellent and reliable resource, as one of the go-to places for information on women's health in the UK.

This isn't only for patients' benefit. "There's a really big need for information for healthcare professionals," stresses Jenny. As an example, she says the drop-off in HRT prescribing in the 2000s was the result of a lack of cohesive, accurate information. "There was the suggestion in the media that HRT gives you cancer – which is very misleading – and it resulted in many women going without something that could be so beneficial because doctors didn't have the full picture. They were too nervous to prescribe because the information they got was incomplete and, in many cases, inaccurate."

Reliance on Dr Google

Women feeling compelled to turn to the internet for help with their health issues is also a theme that the RCOG's women's

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"Specialised online forums (eg, the VBAC one I'm in) are really helpful. They're also quite empowering and help women get support."

"Another concern with wrong information is instructions on cream explaining to rub it on the vagina (which is internal genitalia) – but the tube says it's 'not for internal use'. Basically it means the vulva – external genitalia. A prime example of using incorrect terminology and adding confusion for women."



There is a real need for patients to be directed to trustworthy and clear sources of online information

health strategy is tackling. “It’s a bigger systemic issue if women are being left for too long to deal with something on their own,” Jenny says. “If you’ve been suffering [from a condition] for a long time you do get a bit desperate. You’ll spend hours reading all sorts of things on the internet.”

This is why the strategy’s overarching purpose – to find a way to make a woman’s healthcare journey more seamless and

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“The leaflets I have seen for hysteroscopy, smear tests and pelvic ultrasound are patronising, lying and misleading. The invasiveness of the tests is never acknowledged.”

“One problem I personally find with info is that it’s all really basic when I want a bit of detail. So I also end up searching journal articles sometimes

as well; the introduction sections usually have some helpful info in.”

“The female GP I see for menopause loves it when her patients come in prepared and informed. If they are confused or have incorrect information, she explains why and spends time giving them the correct information and advice.”

joined-up – is so important, as it will have an impact on the way women access their healthcare. Ideally, in the future there will be far less reliance on Dr Google.

Behind-the-scenes data

Information in its purest sense – data – is the world of Jackie Shears, Associate

Director of Data Acquisition at NHS Digital. Her job is to bring together patient data from across the health and social care system to generate publications, statistics and information to go back out into the system. NHS Digital has a role under the Health and Social Care Act 2012 as a ‘safe haven for data’, she explains.

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“I acknowledge there is a lot of rubbish out there but there is also a lot of really helpful information and support; it upsets me when doctors have a blanket very poor opinion of the internet and then a patient says ‘I read online...’ and there’s eye rolling and dismissing of everything said past that point.”

“So many women don’t feel able to stand up to their GPs or consultants and demand better care so they just suffer in silence. We should not have to resort to Dr Google for information – we should be given all the information and support we need.”

Jackie deputised for Sarah Wilkinson, the chief executive of NHS Digital, at the most recent Women’s Health Taskforce meeting. NHS Digital is on the Taskforce because developing a more joined-up healthcare journey for women can’t be achieved without the behind-the-scenes data to back it up. And the desire for more seamless healthcare runs alongside NHS Digital’s plans to transform the usefulness of the data it collects.

“Our HES are widely viewed as world leading in terms of understanding the data in a health system,” Jackie says. “We also have really strong data on maternity, community and mental health. But because we collect it [specifically] for maternity policy purposes or mental health policy purposes, or other policy purposes, we end up with these vertical

silos. It’s then quite resource-intensive to look at a whole pathway.”

The world of healthcare delivery is already changing, Jackie says. “There are integrated care systems setting themselves up out in provider-land. They’re defining roots for the delivery of patient care that are much more joined-up but really tricky for us from a data-collection point of view.”

Jackie and her team are now working on an approach to data collection that focuses on the metadata – the information about information (for example, its legal basis, what rules are applied to it, where it’s held and where it’s disseminated). By developing an accessible registry of metadata, the information can be examined more holistically.

Information journey

Jackie gives an example: “When a woman goes through an episode she might go to several different organisations. She may start with 111, then get advice to go and see her GP. Her GP may make a referral into secondary care and she may have investigations, maybe some surgery. She might go into a community hospital and then have a district nurse visiting post-surgery. Three or four different organisations will be involved in that episode of care.

“Because we gather this data in a vertical fashion, we’ll pick up bits of that episode but won’t understand the start to



O&G professionals can help women navigate the information available

finish of what the episode looks like at all. To an extent, we expect the woman herself to be the navigator of that information.”

Jackie says she’s working to get to a position that when a patient goes through an episode and leaves ‘footprints’ on the IT systems in each organisation, those footprints can be picked up individually and analysed as a whole journey. There are two ways she wants this new approach to collecting data to be used.

“I’m planning to use it to transform secondary usage data so the availability of data for researchers and policymakers is much richer and much more effective, and patients’ experiences then become much more informed,” she explains. This means that research and policy is based on richer data, which can then be fed back into

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STATISTICS

43%

Health information in current circulation is written at **too complex** a level for **43% of working age adults (16-65 years)**



Research from the USA and Europe shows that people with **low health literacy** are more likely to have a **long-term health condition**



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“I found the BPAS and Marie Stopes abortion clinics leaflet very clear and respectful. It describes the medical technical aspects (instruments used, conditions) and the patients’ experiences as well as statistical evidence of the side effects (anything from death to mild mood change). I found that expressing the risk of side effects in terms of ‘1 in X number will have this side effect’ a really good way of putting it in context.”

information sources such as NHS.uk and provide patients with direct access to more accurate information.

The second method is to use this modular approach at a local level, “to enable data about a patient collected by one clinician in one organisation to be more easily accessible by the follow-on clinicians,” she says.

“Data runs through everything,” continues Jackie. “Women’s health is not binary. You don’t have maternity in isolation; our mental and physical health are entwined. Considering endometriosis in the context of mental health and vice versa is valuable. There is a lot to be gained from a more patient-centric approach to collecting data and enabling that richer, more contextual approach.” ●



The **drop-off in HRT** prescribing in the 2000s was the result a **lack of cohesive, accurate information**