Consultation response

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Liberating the NHS: An Information Revolution

About Which?

Which? is an independent, not-for-profit consumer organisation with over 700,000 members and is the largest consumer organisation in Europe. Which? is independent of Government and industry, and is funded through the sale of Which? consumer magazines, online services and books.

Which? has a long history of representing consumers with regard to health, and believes that everyone should have easy access to good quality healthcare. We welcome the opportunity to comment on the proposals contained in the consultation Liberating the NHS: An Information Revolution.

We agree that patients must have access to the information they want in order to make the right choices about their health care - and that information about the quality of care will be key to enabling this.

However, we also believe that the Information Strategy must balance the right of patients and the public to freely access information about healthcare with the need that the data they receive is reliable, and that the integrity of their own private information is maintained.
Key Recommendations

• Health care information should be provided by a single online provider offering a one stop shop for information and advice. Which? recommends NHS Choices for this role.

• Should the Government decide not to pursue a single online provider, we recommend a centrally-administrated accreditation scheme assuring providers that distribute information, data and analysis that can be trusted by patients. This must be promoted both to information providers and to patients.

• Health information must be provided to patients in a range of formats - not only online - with different levels of detail to cater for their varying needs.

• The collection, storage and sharing of potentially sensitive health data must take place within a framework that protects consumer privacy, abides by the principle of data minimisation, and promotes truly informed patient consent.

Our research

In this document we draw on four pieces of consumer research:

The first quantitative survey was carried out online from 2\textsuperscript{nd}-5\textsuperscript{th} March 2010 among 1,974 Which? members in England, to explore their awareness of Local LINks and likelihood to give feedback on local health and social services.

The second was an online survey of 3,507 Which? members carried out from 26\textsuperscript{th} April-4\textsuperscript{th} May 2010 to explore usage of online health information sources.

The third was an online survey with 1,968 Which? members from 26\textsuperscript{th} August-3\textsuperscript{rd} September 2010, to establish consumer views on health care information provision.

The final piece of research in September 2010 took the form of qualitative hall tests, followed by focus groups. All interviews were with members of the general public who had experience of NHS hospital care in the last 12 months. They explored their information needs in relation to making choices about their healthcare.
Q1: What currently works well in terms of information for health and adult social care and what needs to change?

Our May 2010 research with members comparing online information sites shows that healthcare websites perform poorly in terms of satisfaction in comparison to other sectors:¹

Customer scores from recent Which? Member surveys

48% customer score for health information sites isn’t much better than utilities

Members reported that they are most likely to go to health professionals as opposed to websites for health information/advice.² Our qualitative research shows that most people continue to view the GP as the key provider of information about

¹ In our regular customer satisfaction surveys across a wide range of sectors we include two key questions (on satisfaction and recommendation) which are calculated into a customer score so that we can compare different sectors as well as different providers within one sector.
² Online survey of 3507 Which? members 26th April - 4th May 2010
health choices. This is particularly common amongst older respondents, who are used to a long-term relationship with the GP, and those who are less familiar with carrying out their own searches online.

Hard copy information remains important, particularly in relation to GP surgery choice and for those who are not internet users.

Q3: Does the description of the information revolution capture all the important elements of the information system?

Which? is concerned that the current description of the Information Revolution does not capture all the important elements of the information system. There is no detail about how data will be anonymised, how consent will be obtained prior to sharing, and on what data will be collected and made ‘publicly available.’
In addition, there are no clear indications of how data security will be ensured and how the system will be future-proofed against advances in data analysis that could lead to easier de-anonymisation of data.

The consultation envisages data being made available to Universities and research sectors but unanswered questions remain as to who exactly would have access to such data. For example, would the research sector include pharmaceutical companies? Would public accessibility mean that insurers can access the data?

The description also lacks an indication as to how the amount of information seen will differ according to the role of the person accessing it. For example, how will the data patients see differ from the data that is available to care staff, policy makers, and third party researchers?

The description is a vision of the benefits that an open system could bring to both patients and society, but is currently lacking in any recognition of the possible costs. We believe that a detailed cost benefit analysis is required, alongside research with patient market research to identify their key concerns.

Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?

We do not doubt that the benefits such a system could bring are real and have the potential to greatly improve the quality of care experienced by many, including the most vulnerable patients who may require long-term or frequent care. However, we are concerned that the phrasing of this question - expressed in a closed style, and failing to signpost any costs that might accompany those benefits - does not offer patients a space to consider and express their concerns.

We also believe as the Strategy is developed it is essential that patients and the public are given the opportunity to learn more about how their data is collected and stored, who will have access to it, and with which third parties it may be shared. The Government must also address any potential deficiencies in the communications network which may deny access to some.

Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.
The storage of personal and sensitive health data - inclusive of all care a patient has ever received - in a central system has the potential to make data management and control easier and possibly more secure. Yet providing a route of access to that data for health care professionals, the patient themselves, and approved third parties via the internet raises serious questions over access, consent, security, privacy, and consumer awareness. For example, how would the Department of Health obtain patients’ consent to allow their data to be shared?

Department or third party organisation charged with collecting and processing patient data must do so in line with the current legislative landscape, and particularly the Data Protection Act. Any policy decisions with regard to data collection, control, and processing should be informed by the current discussions on the review of the Data Protection Directive by the European Commission that is scheduled for late 2011. This Directive will form the framework within which the UK’s Data Protection Act and therefore the Department of Health’s information revolution will legally be required to operate.

We welcome paragraphs 2.16 and 2.17 of the consultation document, which recognise the crucial importance of data confidentiality and security, and outline the manner in which standards and guidance will be developed. However, we also believe that before any further steps are taken to digitise and share personal sensitive patient data online the Government must undertake a full impact assessment of the policy - with a particular focus on maintaining security in a fast-evolving field and ensuring that patient privacy is not impacted negatively.

The consultation lauds the value of sharing anonymised data with third parties for research purposes. Whilst we do not argue with the premise that allowing researchers and policy-makers access to large anonymised data sets will benefit research and policy decisions, we do question the feasibility of maintaining true anonymity. Given the advances in data analysis and the impact these have on data anonymisation³, how will the Department of health ensure that patient data remains anonymous? Should data become identifiable following release to third parties through technological advances in analysis or by combining with other data sets⁴, how will the Department of Health inform patients that their privacy has been breached?

The consultation document describes the Royal Colleges’ standards for data collection and the Department of Health’s Information Governance Toolkit, which

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explains the controls and policies that organisations should use to manage the records they hold. It also notes the importance of ensuring that compliance is audited - but it does not go into any further detail as to how this will work. If Government’s intention is for the private sector to be involved in accreditation then it must outline exactly how this will function.

Which? is also concerned that personal sensitive data should be treated as confidentially and securely as possible. The more data is passed around, the higher the chance that it is lost, stolen or misused. Minimising the number of organisations with access to this data will therefore be important.

However, paragraph 2.14 seems to suggest that the private sector will be able to develop competing products for the provision of systems for the presentation of data to patients. This may suggest that data would be portable and capable of being moved between data processing frameworks - raising security and privacy questions and questions over data retention.

Which? also has concerns relating to access. Despite the government’s ambitious broadband strategy, and that of the European Commission, there remain large sectors of the UK population that do not have regular access to broadband or to broadband of a suitable speed to enable the provision of high quality and secure medical files.

In addition, there are those who choose not to access the internet or do not have the resources to do so. The number of people who had not accessed the internet in 2010 remains significant at 9.2 million⁵. Therefore, before any plans are set in motion to upload public services a full assessment of access and cost, especially amongst the poorer and more vulnerable sections of society, is required.

If patient and user information is to be supplied by multiple third parties, the issue of tracking will also need to be addressed. Websites can be littered with code - hidden from users - that is designed solely to track movements on that and other web pages. The Government is currently discussing the implementation of the e-Privacy Directive with the European Commission and the Department of Health should monitor these developments closely, as they will impact on the use of tracking technologies on any partner web-sites.

The implications of third-party websites allowing tracking of patients’ browsing of information that could be considered personal and sensitive should be investigated

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by the Department of Health. We believe that accredited third party sites providing health information to patients should be prevented from allowing these tracking technologies on their sites.

**Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?**

Paragraph 2.20 of the consultation document refers to the need to encourage patients to explore information resources in their own time. In 2010 *Which? Computing* investigated the quality of information provided by six leading health information websites and found a varied level of quality. In addition the report found that even when the sites provided reasonably good quality information they could still scare people.\(^6\)

We are concerned that the quality of information resources may be variable: if patients are to be encouraged to do their own research then signposted content must be vetted frequently.

In order that patients become the first line of treatment in their own health care, it is vitally important that patients are also provided with information and support on data privacy and security where they do choose to share this information. This will require clinicians and care professionals to receive training in data protection to complement the training they already receive in talking patients through their treatment options and providing support in decision-making.

**Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?**

In September 2010 *Which?* undertook qualitative research to establish what information people would want to help them choose a new GP or a hospital.\(^7\) For more information on our research and the domains they selected spontaneously, please see the Appendices.

Our results showed that the level of information people are looking for and the format they want it in varies according to need, life stage, condition, and

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\(^6\) ‘Is online medical advice bad for your health?’ *Which? Computing*, November 2010, pp. 8-10

\(^7\) Qualitative hall tests where 30-minute depth interviews took place with 40 adults in Watford and Lichfield from 2\(^{nd}\) – 3\(^{rd}\) September 2010, and 4 focus groups in London and Stockport from 7\(^{th}\)-8\(^{th}\) September. All interviews were with people who had had experience of NHS hospital care in the last 12 months.
seriousness or complexity of condition. Therefore, information must be provided in a range of formats with different levels of detail to cater for these varying needs.

We found that when choosing a GP patients relied heavily - almost totally - on subjective and informal sources. These include word of mouth, reputation and personal recommendation or feedback from other patients. Some may personally visit the surgery to get first impressions. There is virtually no use of or access to more objective measures - whilst some may check facts and information from a website or practice leaflet, it was feedback from other patients that ultimately shaped their judgement:

“You want to know about their reputation, what people think of them, have they had good experiences” (Pre-families, London)

“I’d ask for a personal recommendation but follow it up with a visit to the surgery. It’s very important what people say because it puts you on your guard” (Retired, Stockport)

In reality many consumers will only focus on a few key criteria to make choices, so provision and communication of information will be key to supporting them and preventing being overwhelmed by too many criteria.

When we surveyed Which? members in August-September 2010, the most important piece of information they said they would want when choosing a GP after moving to a new area was their competence, followed by friendliness and attitude of the GP and concerns around convenient access - namely the availability of convenient appointments, the average waiting time and opening hours. Distance from home or work was also important.

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8 Which? carried out an online survey with 1,968 Which? members from 26th August - 3rd September 2010 to establish consumer views on health care information provision online.
Information Which? Members said they needed when choosing a new GP (n=1968)

When we asked patients in our qualitative research about the type of information that would be useful for them in making a choice of hospital, they told us they wanted a combination of factual, statistical and patient feedback. It was essential for this data to be updated regularly. People wanted a simple, clear presentation style enabling them to compare options according to personal criteria.

Patients had innovative ideas for how online information could reflect the patient journey - which they felt was important - including their typical choices and decisions. One concept suggested was a clickable map of the human body where one could select the area experiencing symptoms (for example the knee) and click through to information about knee conditions and knee hospitals.

Subjective sources for choosing a hospital include GP recommendation (which is very important), word of mouth, local reputation (including bad press over issues such as high infection rates or a poor safety record), or patient fora with feedback
from those with direct experience in a particular hospital or of a specific treatment.

In terms of objective sources, patients were more likely to check out specific information, look at individual hospital websites, seek details of consultant expertise, read hospital leaflets outlining services and expertise, and look at relevant statistics on infection rates and survival. Interest in detail increased along with the seriousness or complexity of the condition affecting the patient:

“Distance is less important, if you have access to experts you’re prepared to travel” (Young families, London)

“Are they clean...what about superbugs?” (Retired, Watford)

“If I have a heart problem, I want to go to the hospital that has a high success rate with heart surgeries so I would go for specialities and success rates” (Retired, Stockport)

When we asked Which? members\(^9\) what information they would need to help them in choosing a hospital for a routine minor operation, cleanliness was seen as very important - with 81 per cent selecting it. Information about specific specialisms, performance of the hospital, convenience of access and information about MRSA or other infections were also common selections.

\(^9\) Which? carried out an online survey with 1,968 Which? members from 26th August - 3rd September 2010 to establish consumer views on health care information provision online.
Information Which? Members said they needed when choosing a new hospital for a non-urgent operation (n=1968)

Q14: What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?

We note that there will be a hiatus between the end of the Care Quality Commission care home star ratings system and the development of a new framework, and would be concerned about any lack of up-to-date information on homes available to service users and carers in the interim.

We believe that feedback from service users and carers about the information on outcomes that is important to them should inform the new scheme, and that it should be thoroughly tested with them.
Q18: What are your views on the approach being taken and the criteria being used to review central data collections?

Which? is supportive of the principle of data minimisation - to limit the collection of personal information to what is directly relevant and necessary to accomplish a specified purpose. As such we welcome the proposed approach to review central data collections before collecting more data and particularly the suggestion in paragraph 3.6 of the consultation document that, following the review, data deemed unnecessary will be removed from central data collections.

However, we are concerned that the ambiguity of some of the criteria proposed for the assessment of centrally-held data will threaten that principle. The first of the criteria - that data is essential to and necessarily generated as part of the care giving process - is perfectly acceptable. This is also the case for the fifth criterion, that the data held fulfils a legal obligation. However, the remaining criteria are so wide as to be ambiguous, potentially leaving the door open for a host of unnecessary data to be levered into the central data centre.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

In March 2010 we surveyed Which? members to understand: how many had been contacted to give their view on health and social services in their local area; whether members would be keen to give their feedback on these services if there was an easy way to do so; and whether they were aware of Local Involvement Networks (LINks) operating in their area.

Whilst the majority of members (81 per cent) said they would be likely to give direct feedback to their local authority/health services on the way these services are run in their local area if there was an easy way to do so, only 25 per cent had been contacted by their local authority or health services, or an organisation working on their behalf, seeking views on the way that health/social services are run in the local area and how they can be improved. Only 10 per cent of members were aware of LINks in their local area - and the vast majority (86 per cent) didn’t know if their local network exists.

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10 The survey was carried out online from 2nd-5th March. A total of 1,974 Which? members in England completed the survey.
This Which? research suggests that on the whole there has been a failure by LINks to engage with broad swathes of their local populations so far. Whilst there may well be very good practice in some areas, evaluation will be key to ensuring that HealthWatch and any other new mechanisms for patient feedback perform better.

Successors to LINks must ensure that they communicate their existence to local patients, which may mean more effective targeting - perhaps through a form of social marketing that incentivises patients to give their feedback. They must also consult with patients on how they want to be involved, and ensure that simple methods for engagement are available. One strong incentive to give feedback is communication from services on the changes they have made as a result of previous feedback.

The new GP Commissioning Consortia must ensure that they engage representative groups of patients in helping them to design and commission new services for local populations. In order for patients to have real power, their feedback must be embedded in local structures.

In this survey women and older members were more likely to say they would give their views. Whilst the views of both these groups are important, if this holds true amongst the general population it will be important to devise systems that encourage all patient groups to have an appropriate level of involvement - including men and younger people. Women and older members were also more likely to be aware of local LINks in their area than other members.

Q28: The ‘presumption of openness’ in support of shared decision-making will bring opportunities - but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a service user?

One crucial challenge is that of patient privacy. The consultation document states in paragraph 5.7 that databases will be published routinely and regularly - making it easier for organisations such as those representing patients and service users, to access and analyse data. Which? would like to see more detail in the Information Strategy on: how information and consent to share it will be collected; how information will be anonymised prior to publication; and the network systems that will be used to ensure that data is protected once published.

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11 The survey was carried out online from 2nd-5th March. A total of 1,974 Which? members in England completed the survey.
While we agree that the provision of good quality information to service users will enable them to make better, more informed decisions about their healthcare, we believe that the Government needs to outline exactly how it proposes to do so that patients will not be vulnerable to data breaches.

The ‘presumption of openness’ also raises the spectre of a plethora of organisations repackaging the same data and drawing different conclusions from it - a situation that would be likely to cause consumer confusion and possible detriment.

In our qualitative research, some raised strong concerns about how facts and figures could be presented in a misleading fashion - especially those with knowledge of statistics. As well as concerns about honesty, some patients were concerned that they lacked the skills or context to interpret complex statistics - they suggested national standards were set and explained so that figures could be interpreted correctly.

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

Participants in our focus groups and hall tests were worried about multiple online providers and emphasised the importance of a single trusted provider they could trust to be objective. For many the spontaneous and natural provider was the NHS, while for others an independent provider was preferred due to concerns about objectivity:

“You would only want one site to go through which would ideally guide you through all the choices and that would be your resource…you couldn’t go to each hospital site to compare” (Young families, Lichfield)

“you just want the one place to go.. I trust the NHS over and above anyone else so wouldn't think about looking elsewhere” (Older families, Lichfield)

Which? has already recommended\(^\text{12}\) that a single online information provider is chosen with the following characteristics - taken from the views expressed by the patients in our groups and hall tests:

\(^\text{12}\) Which? (2010) Liberating the NHS (DH) - Consultation response
In light of the fact that NHS Choices is already a popular, well known source of online health care information Which? recommends that this site is chosen as the single online information provider.

Should plans to stimulate a market of data providers go ahead, clear guidance and effective enforcement of data protection laws will go a long way to reduce the risk to personal privacy. Government must clearly describe how enforcement of standards and guidance will be ensured, including how the cost of enforcement will be covered in these times of austerity.

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and ‘intermediaries’? Would factors such as cost and bureaucracy outweigh any benefits?

Should Government decide not to promote NHS Choices as a single online provider, we foresee that quality assurance for health information online - and in any case in other formats - will be essential. We suggest that a centralised approach - administrated by an NHS body - would be the best way to achieve this. Multiple quality assurance ‘logos’ or ‘kitemarks’ may serve to confuse consumers further. In addition, any accreditation must be actively promoted to patients so that they know they can trust information provided under its auspices.

Whilst we appreciate the challenge of funding such work in the current climate, the costs and benefits of opening up the system must be properly assessed before the Information Strategy is published. We support the right of patients to shared decision-making complemented by high quality information. But one does not
become truly informed simply by being presented with information, and whilst some patients may have the skills to sort the wheat from the chaff, others may be dangerously vulnerable to information overload.

As one patient told us:

“Choosing a holiday is easy, you can use reviews and also your own judgement, but health is much harder, you’re not medically qualified not confident and it’s scary territory” (Pre family, London)

In addition, we are concerned that voluntary organisations - especially smaller ones - may lack the financial capacity and human resource to process data and be ‘infomediaries’.

Central accreditation would give patients confidence in the ratings and information that they receive from information providers. It could also be used to demonstrate to patients that the information provider meets the government’s strictest standards on privacy and is not only a trusted source of information but a trusted processor of data. It must, however, not deter smaller organisations from access to being ‘trusted providers.’

FOR FURTHER INFORMATION PLEASE CONTACT:

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Appendix 1

Which? has carried out two pieces of research to establish what information patients really want to help them make choices about their health care and what needs to be put in place to enable the Government’s proposals to work effectively for consumers.

Qualitative hall tests were carried out involving 30-minute individual depth interviews with 40 adults in Watford and Lichfield on 2nd and 3rd September and 4 2-hour focus groups with consumers (6/7 respondents per group) in North London (2 groups) and Stockport (2 groups) on 7th and 8th September. All respondents taking part in the research had experience of GP and NHS hospital care in the past 12 months, either for themselves or someone they care for. The research focused on the ‘pre-family’, ‘young family’, ‘older family’ and ‘empty nester/retired’ life stages.

We asked respondents about their views on choice in healthcare, the information they want in order to choose a GP and hospital, and how they would want such information to be delivered. We also asked them for their feedback on the five themes - access and waiting; safe high quality co-ordinated care; clean friendly comfortable place to be; building closer relationships; and better information, more choice - which had been provisionally selected to develop a short-term patient experience indicator for the proposed Outcomes Framework. We cover this in more detail on our response to the consultation *Transparency in outcomes - a framework for the NHS.*
Appendix 2

Information people spontaneously wanted to know when choosing a GP

- **Proximity to home/location**: Often a key factor and first consideration
  - Some may simply choose on this basis

- **Practice facilities**: Related services, professionals linked to practice
  - Size of practice, number of GPs, locums, languages spoken
  - Linked services, on site diagnostics

- **Professional expertise**: Specific expertise, areas interest (acupuncture)
  - Female GPs
  - Reputation – good diagnoser, friendly, will refer, open, complaints, specialisms

- **Access and service**: Opening hours (early and late opening)
  - Emergency, out of hours service
  - Appointment system:
    - Booking on day, emergencies
    - Vs
  - Booking in advance

- **Communication**: Doctor/patient relationship and interface
  - Attitude and approach
  - Reception and other staff; friendly, welcoming, helpful, flexible, sympathetic
  - Continuity of care

- **Environment**: Good facilities: clean, hygienic
  - Modern, up-to-date
  - Pleasant
Information people spontaneously wanted to know when choosing hospital

**Reputation/status of hospital**
- Good/bad ratings/press/media reports
- Local WOM
- Teaching hospital, local DGH
- MRSA, number of deaths

**Specialist areas expertise - hospital and consultant**
- Pregnancy, childbirth
- Children (paediatric, A&E)
- Centre of excellence
- Good for specific conditions
- Access to experts
- Latest treatments, diagnostics, technology

**Appointments**
- Referral time
- Waiting time for routine tests, diagnostics, appointments

**Cleanliness**
- Reputation for infections, superbugs
- Evidence of hand sanitisers
- Overall impression of environment, clean, bright

**Quality of care**
- Nursing staff, well staffed, attitude, approach, professionalism
- Permanent staff vs locums

**Convenience**
- Location
- Ease of getting there – transport links
- Parking
- Visiting hours

**Facilities/services**
- Modern, up-to-date
- Latest equipment/technology