

Let's talk cancer

#IWACancer

iwa





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Let's talk cancer' is an IWA project in Partnership with
Tenovus Cancer Care and the Jane Hodge Foundation



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The problem



+ Cancer cases in Wales are increasing,

New cases of cancer:
19,026 in 2013
16,921 in 2004 (up 12%)

— Resources for the Welsh NHS decreasing, running costs rising

£ Poorer society

 Ageing population

<p>Around 120,000 people are living with Cancer in Wales, by 2030 this will be 230,000</p>	<p>43% of the Welsh budget is taken up by health and social care</p>	<p>Incidence of cancer in Wales is 20% higher than England</p>
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Most Common cancers in Wales:

Male
 Prostate,
 Lung,
 Bowel,
 Non-Hodgkins Lymphoma
 Bladder

Female
 Breast,
 Bowel,
 Lung,
 Uterus,
 Malignant Melanoma of the Skin

Let's talk cancer

#IWACancer

With population ageing **one in every two of us** can expect to be diagnosed with cancer at some point in our lives.

Foreword

Cancer is a disease that has touched most families. The projections are that incidences of cancer are on the rise and that presents huge challenges for the NHS, and for policy makers.

The number of cancer cases in Wales rose from 16,921 in 2004, to 19,026 in 2013. Alongside this personal trauma is a system trauma - the amount of money available to spend on healthcare in Wales is declining. The Institute of Fiscal Studies have demonstrated that the Welsh health budget faced a cut of 8.6% between 2010 and 2014, and the era of austerity is far from over.

Is it going to be possible to improve the way we deal with cancer whilst coping with rising levels of the disease and diminishing resources?

There are numerous experts pondering this dilemma but we decided this project should seek to explore the untapped expertise of the people with first hand experience - cancer patients and their families.

Based on the IWA's experience of applying crowdsourcing principles to the debate around the future of the UK with our Constitutional Convention project earlier this year, we were confident that the 'wisdom of the crowd' could bring useful insights to the debate around cancer provision.

We partnered with Tenovus Cancer Care and the Jane Hodge Foundation to design a 6-week long conversation to put the principles of 'co-production' into practice. In line with the Health Minister, Mark Drakeford's new philosophy of 'Prudent Healthcare', our project sought to give the patient a voice in redesigning public services.

We assembled a panel of practitioners and academic experts to provide advice and guidance on the development of the crowdsourced ideas in order to create policy recommendations that are practical. We also partnered with a diverse range of stakeholders throughout the project to try and ensure both

wide engagement and expert advice. The breadth and range of skills and expertise offered by the panel and partners on the issues raised by the 'crowd' led to the development of our 6 final recommendations which are presented in this report.

What is striking about the final recommendations is that they are not new or groundbreaking, and certainly are not wildly expensive or unattainable. We anticipated that the discussion would reflect the political and media debate around cancer care and focus primarily on the availability of new drugs. Whilst this did arise it was at most a sub-theme and did not ultimately win enough popular support amongst 'the crowd' to be shortlisted. The ideas that resonated instead were related to improving the patient experience and communications with patients and their families.

The ideas that originated from patients and their families are very familiar ones. Indeed, they are issues that have been raised time and time again by different groups across the range of NHS services, but clearly the NHS hasn't sufficiently reacted to problems that people have raised in the past. Why?

Analysts have come up with the idea of double loop learning to explain how complex organisations learn, or fail to learn, to change effectively. When applied to the NHS and the issues raised in our project it suggests that solutions to well known problems have been devised without taking into account the organisational culture and game-playing. By basing proposals for change on incomplete and distorted feedback the underlying problems are not addressed, and the problems soon reassert themselves. Proposals to effectively embed change need to take this into account and build in 'double loop' learning to anticipate the complex challenges.

Understanding these issues could provide the foundation for the NHS in Wales to build a service in which the patient feels valued, and is finally able to address patient concerns raised around receiving specific, timely and accessible information about patient contact with the health service.

Health care is about cutting edge technology and brilliant science; but it is also about getting the simple things right, and remembering that every patient is also a person. While addressing our recommendations in this report will go some way in solving the issues our participants face, we also want this report to act as a call for NHS Wales to look at systemically putting the patient experience at the forefront of health care.

Prof Marcus Longley,
Chair, IWA Health & Social Care group

Lee Waters,
Director IWA

Analytics

www.letstalkcancer.wales:

132 Registered users
101 Posted ideas
241 Posted comments

Paper submissions:

32 Paper-based ideas
3 Physical
 consultation sites

> www.letstalkcancer.wales

2,875 Total users
46,146 Page views:

> ClickonWales

10 Articles
2,498 Page views

> [Twitter](https://twitter.com)

217 Tweets
457,523 Potential reach:

> [Facebook](https://facebook.com)

80,067 Reach

Demographics



Gender of registered users

■ female: 70 (53%)
 ■ male: 23 (17%)
 ■ didn't say: 39 (30%)

(Of the 132 registered users, only 2 were based outside Wales.)



Age of registered users:

■ 18-24: 2 (2%)
 ■ 25-34: 10 (8%)
 ■ 35-44: 18 (14%)
 ■ 45-54: 42 (32%)
 ■ 55-64: 23 (17%)
 ■ Preferred not to say: 37 (27%)

Let's talk cancer ideas

What we did

We asked each contributor to the *Let's talk cancer* project to tell us about one good experience of cancer care in Wales, and one bad one; and to suggest an idea for improving it.

As an independent think-tank, working with trusted charity Tenovus Cancer Care, we offered a 'safe space' where people could candidly discuss any aspect of their cancer experience. Over a six week period between 8th June and 17th July 2015 we had some 9,000 engagements with the project and received 133 separate suggestions for improvements from people based on their first hand experience of cancer care in Wales.

The ideas came through a specially designed website hosted by crowdsourcing specialists, Crowdcity, and supplemented with paper based questionnaires for patients to fill in whilst they were waiting for treatment with the help of our partners - Maggie's Centre in Swansea, Prince Philip Hospital in Llanelli, University Hospital of Wales, and Velindre Cancer Centre.

The ideas that were generated were voted on by 'the crowd' on the *Let's talk cancer* website. Some 9,000 viewed the site over the course of the project and took part in the process. We took the 12 highest rated ideas and discussed them with our expert panel of practitioners from a range of disciplines to test their practicality. The panel agreed a shortlist of 6 ideas which we tested further with the general public through the IWA's website to agree our final recommendations.

“We offered a 'safe space' where people could candidly discuss any aspect of their cancer experience.”

Project Conclusions

Our recommendations are:

- 1** Patients should be given accurate information about delays to appointments on-the-day so that they may better manage their time during the delay period.
- 2** Patients should be able to easily access their notes and any letters relating to their case.
- 3** Financial support and information should be readily and easily available for people affected by cancer. This could be done through an established referral pathway, where patients and their carers are provided with advisor details in an accessible format. Welsh Government and health boards should work with the third sector to ensure this support is available for all affected by cancer.
- 4** Patient transport provision should be clearer and more flexible prioritising the patient experience, with an emphasis on efficiency and timeliness. Different transport providers, including third sector services, should be used where appropriate. Gaps in existing provision should be mapped.
- 5** Where possible some elements of care should be delivered locally. For example regular appointments for checks on blood pressure and dressing changes could be delivered at a primary care level and any results sent directly to the relevant consultant.
- 6** Patients' records should be available to all practitioners treating the patient throughout their care.

A consistent theme throughout this project has been communication and better access to information for all concerned, patients and professionals. We believe that many of these recommendations reflect this, and policy makers should put these issues at the forefront of cancer care in Wales.

Let's talk cancer recommendations

Each idea is presented here in its original form, with the corresponding policy recommendation and a summary of the discussion and guidance from experts and practitioners that led to the finalised recommendations.

One

Text / Phone patients to alert them in advance of long delays to appointment times



1 Text / Phone patients to alert them in advance of long delays to appointment times Suggested by David John Sutherland

“If there are delays with appointment times then why not text or phone the carer/patient in advance to advise them that there is a one or two hour delay and they can make a choice as to how to manage their time.”

This issue, like many raised under the consultation, is not a new concern for patients and nor is it specific to cancer care.

Recognition of the benefits to the NHS and patients of text-based appointment reminders is now widespread and there is movement on this issue in Wales, although provision is piecemeal. The My Health Online website allows registered patients to interact with their GP surgeries to book and cancel appointments, request repeat prescriptions and update personal information.

Provided by GP practices in collaboration with NHS Wales this basic provision is a positive step forward for patients where it is available. A further shift towards providing patients with personalised appointment notifications in Wales include the Welsh Ambulance Service’s plans for opt-in text-based hospital transport reminders.

Notification of delays to appointments, as distinct from appointment reminders is much more complex, however. Appointment delays are a common problem for patients across a range of NHS settings, from GP surgeries through to hospital appointments. Basic appointment reminders are a very welcome step forward for patients in Wales, and are a vital NHS tool for reducing the number of ‘Did Not Attend’ appointments which in turn reduces delays in the overall system. However, simple appointment reminders do not present the patient with the kind of information necessary to help them plan their time around delays.

Services sitting outside health settings, such as Uber, are driving patient expectation around communication and appointment status updates. Uber operates a global taxi network, and provides a mobile experience that allows customers to request a taxi pickup. Customers are kept up to date with text messages as the status of their request changes - when a driver accepts the request, when the driver is less than a minute away, and if the ride has been cancelled for any reason. These innovations

“If you are working, appointment delays can be really damaging. Even if you are not working it is still extremely inconvenient and upsetting. It can also impact badly on people’s travel arrangements, whether you arrive by bus, car or even ambulance”

Chris J

also exist in the healthcare field, for example, InQuicker, an online self-scheduling system available in the US which lets patients check-in for estimated treatment times at ERs and Urgent Care Centers or book appointments for healthcare services. Such innovations were cited a number of times in discussions around this suggestion, and another shortlisted *Let’s talk cancer* idea concerning hospital transport notifications.

Discussions with the panel and other experts within the Welsh NHS acknowledged that appointment waits are an historic problem that the NHS has failed to address satisfactorily on a systematic basis. Previously, it seems that the best solutions offered were created on an ad-hoc basis, and not available in all settings to all patients, or dispatched early enough. An example of an historic NHS response that was cited was where a south Wales hospital developed a tannoy call system to call patients back for their delayed appointments from elsewhere in a hospital, for example the cafeteria. Whilst all efforts to improve the patient experience are to be welcomed, this kind of response clearly falls short of patient expectation and technological possibility in 2015.

The technology exists to create a delay notification system for the Welsh NHS. However, implementation is lacking.

The Welsh Ambulance Service is currently setting the standard in this area with the development of a phased patient alert programme for hospital transport. Phase 2 of their plans, due early 2016, will allow a 15 minute “put your coat on” text and allow two way texting to allow a text to be sent by the patient to cancel transport without the need to ring the booking centre.

Currently, the Welsh NHS believes that it doesn't have the correct technological interfaces in place to support the development of such a complex patient notification system. It is deemed beyond the capability of Wales' current NHS systems to provide such personalised and detailed patient information direct to patients because the necessary infrastructure is not in place.

This must be challenged. In the meantime, more should be done by in every health setting to inform the patient of the length of delay in order that they can manage their time better during the wait period instead of having to wait until called.

> **Recommendation:**
Patients should be given accurate information about delays to appointments on-the-day so that they may better manage their time during the delay period.

Two

Patient notes
should be made
available to all



2 Patient notes should be made available to all Suggested by Annie Mulholland

“In Wales patients don't automatically receive their patient notes. Access to patient notes is by no means consistent or clear. I discovered the Welsh Patient Rights posted on the Citizen's Advice website and one of these is that patients have the right to receive a copy of their notes.

Before leaving the Welsh NHS I phoned my cancer centre to ask for my Patient Notes. I was told I had to write a letter asking for them. This may well be a barrier for some. In due course I received a letter in response telling me I could be charged £50 for photocopying. This could be an insurmountable barrier for some patients. I did finally receive my Patient Notes and no charge was made.

If access to Patient Notes is a Patient Right it should be a right for all without cost or condition.

Some patients in Wales tell me their notes would be full of gobbledygook. I receive a note of every decision, every meeting and all letters sent to my GP.

I have direct experience of the benefits of such a system. When my former hospital made an 'admin error' and forgot to order one of the dual agent chemotherapies I should have received at first line, had I received my patient notes I could have dealt with the error before it was too late to rectify.

I never did receive the gold-standard chemotherapy for ovarian cancer in Wales because by the time the error was discovered, during my subsequent visit to the hospital, the locum oncologist told me there were no more 'places' left to administer this infusion for several months and that it would be bad for me to undergo chemotherapy over what would then be a 9 month period.”

“It should be up to the patient to decide on levels of confidentiality and not the NHS making a global decision on what is best for us”

Annie Mulholland

This issue, like the idea for delay notifications, is central to the patient experience of the Welsh NHS, and is also hampered by the Welsh NHS's technological infrastructure.

The right to access patient notes already exists, but currently the Welsh NHS is unable to meet this without disproportionate effort and cost implications. Again, digital technology provides solutions, at speed and at low cost. There are already many apps and businesses globally that are providing the means for patients to access their own medical notes such as Open Notes, and numerous open source-based systems.

Indeed, some smaller countries are in the vanguard on this issue. For example, Israel's health-care system is fully digitised; all doctors use electronic medical records, and patients there have access to their data.

Wales though, is lagging on this issue. From April 2015, all GPs in England gave their patients online access to summary information in their records. The ambition is that by 2018 every citizen falling under NHS England's jurisdiction will be able to access their full health records at the click of a button, detailing every visit to the GP and hospital, every prescription, test results, and adverse reactions and allergies.

Practitioner discussion on this topic supported the principle of the patient being able to freely access their notes and any records relating to their case if they wish to. However, there is little confidence that the Welsh NHS systems would be able to deliver a workable IT solution in the foreseeable future. Furthermore, there is concern for the ethical implications of providing access to patient notes, which ranged from protecting patients who did not want to access their own notes, protecting patient data/information and complexities stemming from the availability of biological information to families and businesses in the future.

Let's talk cancer consulted with a health professional working in improvement within a local health board on this issue. Their advice was that careful consideration needs to be given to measures that could make a rapid impact with little associated cost/outlay. Clarity on the meaning of making 'patient notes available' was also a concern. It was noted that not all records are useful to the patient, much of it is there as an historic record in the event of legal challenge, but correspondence, for example, would be beneficial to the patient. Some work is being carried out by health boards to copy clinical letters to patients, something that has been long in place in paediatrics, and would have immeasurable benefits quickly as can be relatively easily undertaken. It was suggested that this flow of information could be provided on-line via the Welsh 'My Health Online' portal that provides patients with the opportunity at present to book appointments and order/request repeat prescriptions.

From a patient experience point of view, it is crucial that the NHS in Wales commits to providing the same access to patient notes as that which exists for patients in England. The implications of differing policy commitments are that Welsh patients experience an unequal service to their English counterparts.

> Recommendation:
Patients should be able to easily access their notes and any letters relating to their case.

Three

Claiming benefits
could be clearer,
fairer and quicker



3 Claiming benefits could be clearer, fairer and quicker Suggested by Jayne Mason

“Many people diagnosed with cancer do not realise what benefits and help is available for them, and they are also too ill to complete lengthy claim forms or to pursue any claims.”

Currently provision of support for benefit claimants who are affected by cancer is made on an ad-hoc basis. Although many third sector organisations have excellent support services available, including Tenovus Cancer Care, Macmillan and Maggie’s Centres, these rely on the patient or their family to initiate the support. Concerns were raised by practitioners about “good patients” missing out on transformative financial support in this scenario because they do not want to burden the system by claiming benefits that they might not feel ‘entitled’ to.

Tom Dyer, Cancer Support Advisor for Tenovus Cancer Care and a specialist on welfare benefit law made an expert contribution to *Let’s talk cancer* on this specific topic, proposing that a default referral policy be implemented, “where all patients are provided with independent advisor details in their consultant or nurse packs, [and] avoids the risk of anyone falling through the net and being left to panic about their health and wellbeing”.

There are innovative examples of other types of welfare intervention and support currently being explored within the health system in Wales. Age Cymru Gwent has been piloting a scheme of embedding advisors in GP surgeries in Newport to proactively identify patients in need of early intervention, including welfare rights advice. The project has succeeded in identifying a significant amount of unclaimed welfare support.

Innovative schemes such as this offer alternatives for how we currently operate in other areas of the health service, and its lessons could be explored for people affected by cancer or other illnesses.

“I think you’re right that people are not claiming benefits to which they’re entitled.”

Annie Mulholland

- > Recommendation:
Financial support and information should be readily and easily available for people affected by cancer. This could be done through an established referral pathway, where patients and their carers are provided with advisor details in an accessible format. Welsh Government and health boards should work with the third sector to ensure this support is available for all affected by cancer.

Four

Access to transport



4 Access to transport

Suggested by Kate George

“Access to transport is a huge issue. I know ambulance transport can be arranged but I know that when these services are utilised, elderly and vulnerable patients are often away from their homes for 12 hours or more which can only make a gruelling situation even worse. So I think that more flexible transport options should be made available for those most in need of it.”

The Welsh Ambulance Service’s non-Emergency transport provision supports around 1.4 million journeys every year, enabling patients to access outpatient, day treatment and other services at NHS Hospitals. People affected by cancer in Wales meet the criteria for non-emergency patient transport provision under the All Wales Protocol for Non-Emergency patient Transport Eligibility Criteria.

Despite numerous reviews into non-emergency transport, including the 2014 report on non-emergency patient transport services in Wales, the Griffiths’ Review, and an evidence review carried out by Welsh Institute for Health and Social Care in 2012, access to transport is a significant issue for people affected by cancer. As the idea suggests, patients can feel that the transport provided to enable them to access their treatment is sometimes inefficient, and lengthier than necessary.

From April 2016, the Welsh Ambulance Service will have new targets for patient transportation, which emphasises timeliness, including a 60 minute target for collection of the patient after their treatment. This will be a positive step, if met, for this type of provision.

The practitioners panel agreed with the idea that more flexible transport options should be made available in order to improve patient experience, exploring possibilities of other provision, beyond the ambulance service. There was concern that patients often did not understand their current rights, or how to access Welsh Ambulance Service Trust patient care services. Panel members discussed historic solutions and the possibility of providing accommodation to patients who have vast distances to travel and treatment over a set period of time. The panel identified some excellent examples of local voluntary sector groups organising transport to and from treatment, including that operated by Cancer Aid Merthyr Tydfil. An issue with the provision of third sector services is clearly funding and the availability

“What we need is a range of options for transport, depending on the patient circumstances. We don’t always need to deploy an ambulance. We could have car service, a minibus service, small sit up ambulances and keep the bigger ones for emergency and serious need”

Angela Elniff-Larsen

of services across Wales. While excellent provision is in place via organisations such as Cancer Aid Merthyr Tydfil, these services are not available in all areas across Wales. Jon Antoniazzi, Policy Officer for Tenovus Cancer Care called for all such services to be mapped out in order to identify gaps in provision in a comment on Click on Wales. With some health services being moved or closed, accessing services will become an increasingly pressing issue in Wales. This further underlines the need for Welsh Government to map existing provision.

Consultation with Nick Smith, Interim Assistant Director of Operations at the Welsh Ambulance Service, on the issue of improved access to non-emergency patient transport revealed that Health Boards, the Welsh Ambulance Service and the Welsh Government are “nearing the end of a piece of work that has identified suggestions as to how hospital transport can be improved and changed in the future. One of the key recommendations, based on feedback from patients and relatives is that patients attending hospital should have an ‘enhanced’ service. This has been incorporated into a number of recommendations. Other recommendations made are that that different transport providers should be used where appropriate and better access to information and enhanced online services”.

> Recommendation:
Patient transport provision should be clearer and more flexible prioritising the patient experience, with an emphasis on efficiency and timeliness. Different transport providers, including third sector services, should be used where appropriate. Gaps in existing provision should be mapped.

Five

Bringing
services closer
(Sometimes it's
the Simple Stuff)



5 Bringing services closer (Sometimes it's the Simple Stuff) Suggested by ShanEv

“Having recently been through my third cancer diagnosis some of the simple things would make life much easier. For example, bringing care locally wherever possible. I had a drain in for 19 days post surgery, once I had left hospital I, and my driver, had to make a round trip of over 40 miles 3 or 4 times a week to have the bag changed.

Why couldn't this have been done either at local hospital (not a district general hospital) or my local surgery? I could even have changed it myself and emailed photo/measurement in if needed. Making patients and their families spend hours and £££ on these types of journeys is unnecessary and delays recovery.”

The principle behind this idea was accepted by the practitioner panel as a matter of common sense. Discussion on the issue by the panel felt that routine aspects of care, such as dressing changes and blood pressure checks, should be administered as close to the patient as possible, however, the specific example of care presented in the idea around changing a drain did raise doubts from the panel. Further discussion amongst the panel acknowledged that Wales has challenges with regard to geography and population density, and Tenovus Cancer Care’s mobile units were cited specifically as an example of a way of meeting those challenges. However, it was felt that more could be done given that “we are a small country and should take advantage of that by becoming an integrated and joined up service, with patient welfare at the centre”¹.

Whilst in agreement, Dr Phil White, GP, expressed concern that the system is currently running at capacity, adding that “resource would be needed to train additional community / practice nurses to undertake these relatively straightforward tasks”.

Kath Elias, Macmillan Team Lead Physiotherapy Specialist, noted that people affected by cancer often travel long distances for treatment and rehabilitation which can often be counterproductive. She also noted that there are currently not enough specialists to have a presence in all healthcare settings. She suggested upskilling non-cancer specialists as one way forward, but acknowledged that they will still

“Twin family events with cancer showed need to have major centres for operations centralised but subsequent follow up visits for treatment and consultations should be far more local and regionalised”

Rob Roberts

often be ‘scared’ of cancer, and the patient may not receive the best care that is possible for them.

Annamarie Nelson, Scientific Director of Marie Curie Palliative Care Research, suggested some issues covered by this idea could be managed with telephone support.

The practitioners panel agreed with the crowdsourced suggestion, and agreed the recommendation that care should be delivered as locally as possible for people affected by cancer.

> **Recommendation:**
Where possible some elements of care should be delivered locally. For example regular appointments for checks on blood pressure and dressing changes could be delivered at a primary care level and any results sent directly to the relevant consultant.

1 Stephen Thomas, *Let's talk cancer's* Practitioner Panel patient representative

Six

Information sharing across the services - How to support out of hours GPs



6 Information sharing across the services - How to support out of hours GPs Suggested by Dorothy E

“When I was undergoing chemotherapy and radiotherapy, I had to contact my GP's out of hours service. Whilst they were helpful and professional they didn't know anything about me or my treatment plan and were working 'blind' without access to notes. Why can't GPs have access to the record system so that they know something about your treatment, or better still couldn't they have access to a specialist opinion during weekends? Through my work in the NHS I am aware that Scotland has a dedicated helpline linked to NHS 24 service for patients undergoing chemotherapy or radiotherapy to provide this backup. Couldn't Wales do the same?”

This idea is yet another example of the crowd expressing a desire for an improved patient experience. Discussions and research on this issue overlapped significantly with work to develop *Let's talk cancer's* recommendations to Text / Phone patients to alert them in advance of long delays to appointment times and that patient notes should be made available to all. The panel identified the need for patient information stored by the NHS to be more easily accessible in order to help address this issue as well as those mentioned above.

A digital innovation relevant to this idea is HealthLoop, which aims to “keep doctors, patients and caregivers better connected between visits by offering clinical information and peer-reviewed follow-up plans that aim to automate the routine aspects of care, while tracking patient progress and monitoring clinical areas of concern.”² The system was developed in the US by a doctor to “both save doctors time and improve the quality of outcomes for patients by helping to extend the doctor-patient relationship outside the exam room and by keeping all parties involved connected between visits.”³

2 & 3 HealthLoop Lands \$10M To Help Doctors Better Track And Engage Patients Between Visits: <http://techcrunch.com/2013/12/09/healthloop-lands-10m-to-help-doctors-better-track-and-engage-patients-between-visits/>

“In this day and age we simply should not be trying to manage such a diverse range of high tech treatment regimes with 1950’s paper based filing systems”

DavidClinch

A GP member of our Practitioner’s Panel, Dr Phil White, noted that an Individual Health Record (IHR) system exists for Welsh patients, which provides a summary of your GP record, which will let GPs and nurses working in Out of Hours Service see some basic information about patient medical history. This is reportedly currently available to Out of Hours services, although this doesn’t tally with the experience of the crowd. Furthermore, the record lacks detail and only provides information covering 2 years which for some patients may not be sufficient information to receive the best out of hours care. The fact that the information is currently held by individual surgeries is a considerable barrier to change.

When compared to the enhanced patient experience offered by Healthloop, it is clear that Wales’ Individual Health Record has a long way to go if it is to meet patient expectations around the affordances of digital technology for their care. This needs to be challenged to ensure blockages in the system are cleared.

**> Recommendation:
Patients’ records should be available to all practitioners treating the patient throughout their care.**

Methodology



Methodology

Let's talk cancer was conceived as a multi-platform project which used crowdsourcing techniques to generate opinions and ideas from participants. This report outlines the 6 final recommendations that are being made by the project and the process by which they came about.

The crowdsourcing project was launched on June 8th 2015, and functioned primarily as an online consultation that asked people affected by cancer for their ideas on how to improve treatment and care in Wales, based on the care they have experienced. The website, letstalkcancer.wales used 'crowdsourcing'⁴ technology to simply ask participants for an example of care that had been good, an example of care that was bad, and their idea to improve future care in Wales.

We also offered boxes and forms to submit non digital responses at leading cancer care facilities and groups including the Maggie's Centre in Swansea, Prince Philip Hospital in Llanelli, University Hospital of Wales, and Velindre Cancer Centre.

133 ideas were submitted in total and, following an online public vote, the 12 most popular ideas were longlisted. We then published these 12 ideas on our popular comment site Click on Wales, along with responses from the practitioners, to gather further comments on the ideas here. Taking the 12 longlisted ideas, we consulted with the public via Click on Wales, and our practitioners to develop these into six shortlisted practical policy recommendations.

Project activity resulted in approximately 9,000 engagements with Let's talk cancer over 6 weeks. This includes the number of users on Letstalkcancer.wales, number of visitors, unique page views on relevant Click on Wales articles, individual Twitter users and Facebook engagements.

4 Crowdsourcing means to obtain information or input into a particular task or project by enlisting the services of a number of lay people, either paid or unpaid, typically via the Internet.

Crowdsourcing Ideas

The *Let's talk cancer* website (<http://letstalkcancer.wales>) functioned as a forum for people affected by cancer allowing members of the site to suggest ideas, 'like' or 'dislike' these ideas, comment and to join the discussion. The project utilised functionality created by Crowdcity for the consultation and social networking aspect of the project in order to engage with anyone who had experience of the cancer care system in Wales - patient, carer or health professional.

The website received 46,146 page views during the project's 6 week lifespan from 2,691 unique users. Visitors were highly engaged, spending an average of 4.35 minutes browsing the site and viewing an average of 10 pages per session. A total of 132 individuals registered as users of the website. Although this is a relatively small number of registrations overall, those that did register were very engaged. In the context of the '1 percent rule' of online participation, otherwise known as the 90-9-1, where only 10% of a website's users participate while the other 90% of the participants only view, these statistics show strong levels of engagement & interest since all participation on *Let's talk cancer* runs at around 20% of website visitors. This, coupled with the amount of time spent onsite along with number of pages visited, shows a highly engaged audience.

Let's talk cancer also accepted ideas via paper suggestion boxes located at 3 treatment centres in south and west Wales. 133 ideas in total were submitted during the consultation period which ran from June 8 - July 17 2015.

101 ideas were submitted online at with a further 32 paper-based ideas received directly via suggestion boxes and the postal service.

Awareness Raising

Throughout the consultation, social platforms such as Twitter and Facebook were used to raise awareness of the project and encourage participation.

Let's talk cancer's Facebook activity (paid and organic) generated a combined reach of 80,067 individuals with 3441 engagements which includes website visits, likes, shares and comments.

Let's talk cancer's Twitter campaign consisted of 217 tweets sent by 45 users using the #IWA cancer hashtag, generating 1,126,790 impressions, producing a potential reach of 457,523 twitter users.

A number of posts were also published on Click on Wales, the IWA's comment and analysis platform, throughout the campaign. These included a special series of posts giving expert/practitioner responses to the 'crowd's' ideas. A total of 2,498 individuals viewed the 10 related articles that were published to Click on Wales during the campaign.

Practitioners Panel & Accessing Expertise

The *Let's talk cancer* project was developed and managed by a small steering group comprising the Chair of the IWA's Health & Social Care group Marcus Longley (Professor of Applied Health Policy at the University of South Wales), Jamie Hayes (Director of the Welsh Medicines Resource Centre), Dr Ian Lewis (Director of Research and Policy, Tenovus Cancer Care), Jon Antoniazzi (Policy Officer, Tenovus Cancer Care), along with IWA project officer Angharad Dalton, Policy Manager Jess Blair and Director Lee Waters.

The steering group recruited a broad based practitioners panel to ensure that the whole cycle of cancer care was represented (full membership of the panel is set out in Annex 1).

Panel members were located throughout Wales and worked remotely for the most part, submitting their comments and views either directly to the *Let's talk cancer* website, via email or telephone. Two practitioner meetings were held during the course of the project; one at the start, and one following the consultation's close. These meetings allowed us to explore options to shape the experimental project, and to efficiently access panel expertise.

Let's talk cancer also engaged with expertise beyond that belonging to the Practitioner Panel to develop the project's recommendations, contacting professionals directly to discuss the crowdsourced ideas and develop our responses. We also engaged with other Third Sector organisations that support cancer patients, such as Maggie's Centres, Velindre Cancer Centre, Carers Trust Wales, Macmillan, Welcome to the North Wales Cancer Network Patient Forum, and Marie Curie.

Project process

The online consultation closed on July 17 2015, and the 12 most popular ideas were shortlisted for development following a public online vote. The following ideas made the shortlist:

- > Text / Phone patients to alert them in advance of long delays to appointment times
- > Patient Notes should be made available to all
- > Access to transport (should be improved)
- > Claiming benefits could be clearer and fairer (& quicker)
- > Sometimes it's the simple stuff (Bringing services closer)
- > Information sharing across the services (Out of hours services and how to support GPs)
- > Improve information for newly diagnosed cancer patients
- > A permanent feedback mechanism
- > Hospital transport notification
- > Focus on the prevention and early detection of skin cancer

- > Joined up patient information
- > Respect Patients' Input in Consultation

A mixture of qualitative and quantitative techniques were used throughout the development process in order to arrive at *Let's talk cancer's* final recommendations. These included practitioner panel and expert discussions, online meetings, phone interviews, face to face meetings, research and a panel vote. This phase of the project also saw a number of practitioner responses published to the Institute of Welsh Affairs' comment and analysis blog, Click on Wales in order to take the discussion to as wide an audience as possible. These response pieces were also captured and published on the *Let's talk cancer* website.

A meeting of the practitioner panel took place on August 3rd 2015. The meeting discussed research findings, shared expert knowledge and voted to select the project's recommendations. The panel discounted ideas on the basis of viability, universality and need. Each idea was discussed and panel voted either in favour or against including each one in the final recommendations. In summary the shortlist was reduced to list on the basis of the following group reasoning:

- > The idea calling for hospital transport notifications was discounted on the basis that the Welsh Ambulance Service is working on a programme of implementation for this very request.
- > The idea calling for respect for patient input in consultation related too specifically to Velindre, and did not apply to other cancer treatment settings.
- > The idea calling for the prevention and early detection of skin cancer was deemed to be a basic principle necessary for all cancers not only skin cancer, requiring heavy investment in major public health campaigns.
- > The idea calling for joined up patient information was necessary to the achievement of a number of the adopted recommendations.
- > The idea calling for a permanent feedback mechanism was recognised as good by the practitioners, but they felt that it needed further development and scoping, and as such was not approved for the final shortlist.
- > The idea calling to improve information for newly diagnosed cancer patients was recognised as a big issue in cancer care in Wales, however the practitioners felt this should be partly addressed by new work being pursued on the role of the key worker, within the Cancer Delivery Plan.

Annexes

1-2

Annex 1: Membership of Practitioner Panel and Partners

Practitioner Panel

Naomi Horne

Macmillan Lead Lung Cancer Nurse

Sharon Hulley

Macmillan Skin Cancer Clinical Nurse Specialist

Annmarie Nelson

Scientific Director Marie Curie Palliative Care Research

Deborah Fitzsimmons

Health economist

Ceri Phillips

Health economist

Gareth Thomas

Radiographer

Prof Phil Routeledge

Professor of Clinical Pharmacology

Allison Williams

Chief Exec of Cwm Taf UHB

Dr Catherine Bale

Oncologist

Stephen Thomas

Patient

Malcolm Mason

Oncologist

Anna Evans

Occupational Therapist, Caerphilly

Melanie Thomas

Physiotherapist

Kathryn Elias

Macmillan physiotherapy specialist

David Williams

GP Holyhead

Julie Davies

Macmillan End of Life Care Co-ordinator ABMU

Phil White

GP, Menai Bridge, BMA representative

Dr Rachael Barlow

Clinical Leader/Clinical Academic at NHS/Cardiff University

Sarah Hughes

Centre Head, Maggie's Centres

Advisory partners

Dr Gareth Rees

Retired Consultant Oncologist

Nick Smith

Welsh Ambulance Services NHS Trust

Jamie Hayes

Director of the Welsh Medicines Resource Centre

Tom Dyer

Cancer Support Advisor for Tenovus Cancer Care

John Frankish

Improvement Lead, Aneurin Bevan Continuous Improvement

Prof Marcus Longley

Chair, IWA Health & Social Care group & Professor of Applied Health Policy at the University of South Wales and Director of WIHSC

Jon Antoniazzi

Policy Officer, Tenovus Cancer Care

Dr Ian Lewis

Director of Research and Policy, Tenovus Cancer Care

Lee Waters

Director, Institute of Welsh Affairs

Jess Blair

Policy and Projects Manager, Institute of Welsh Affairs

Angharad Dalton

Digital Project Officer, Institute of Welsh Affairs

Annex 2: *Let's talk cancer* Ideas Shortlist

> Patient Notes should be made available to all

Suggested by AnnieMulholland

In Wales patients don't automatically receive their patient notes. Access to patient notes is by no means consistent or clear. I discovered the Welsh Patient Rights posted on the Citizen's Advice website and one of these is that patients have the right to receive a copy of their notes. Before leaving the Welsh NHS I phoned my cancer centre to ask for my Patient Notes. I was told I had to write a letter asking for them. This may well be a barrier for some. In due course I received a letter in response telling me I could be charged £50 for photocopying. This could be an insurmountable barrier for some patients. I did finally receive my Patient Notes and no charge was made. If access to Patient Notes is a Patient Right it should be a right for all without cost or condition. Some patients in Wales tell me their notes would be full of cobbledy-gook. I receive a note of every decision, every meeting and all letters sent to my GP. I have direct experience of the benefits of such a system. When my former hospital made an 'admin error' and forgot to order one of the dual agent chemotherapies I should have received at first line, had I received my patient notes I could have dealt with the error before it was too late to rectify. I never did receive the gold-standard chemotherapy for ovarian cancer in Wales because by the time the error was discovered, during my subsequent visit to the hospital, the locum oncologist told me there were no more 'places' left to administer this infusion for several months and that it would be bad for me to undergo chemotherapy over what would then be a 9 month period.

> Access to transport

Suggested by Kate George

Access to transport is a huge issue. I was lucky enough to have the support of a local cancer care charity who organised volunteer transport for my radiotherapy appointments in Velindre, which were daily for 4 weeks. I kept working during treatment and would never have been able to do this if I hadn't had this support - I would have been too exhausted and simply wouldn't have been able to afford the daily 40 mile round trip. It makes me wonder how people who are less independent can possibly manage to get to appointments as I needed this support and I am relatively young and fit.

I know ambulance transport can be arranged but I know that when these services are utilised, elderly and vulnerable patients are often away from their homes for 12 hours or more which can only make a gruelling situation even worse. So I think that more flexible transport options should be made available for those most in need of it.

> Hospital transport notification

Suggested by JohnGreenaway

The possibility of getting hospital transport to Velindre was brilliant - having to go in every day for radiotherapy for a couple of months, shortly after surgery (so unable to drive) is stressful enough, but aid in transport is great.

Issue:

However the process isn't very streamlined from the user's point of view. It would often take up most of the day - you're only told am or pm, which can be very tiring when you've little energy. And when an ambulance/taxi shows up and you've 3-4 more people to pick up, pretty much every day there was one of those trips that ended up empty handed or delayed - the person either wasn't there, forgotten or wasn't ready.

Suggestion:

So the suggested improvement is an automated text or email when they collect the previous patient and are on their way to you. It would let people get ready in time. Similar to the mobile apps taxi companies use (Dragon Taxis, or Uber). Ideally it would also say what the transport is (ambulance/taxi licence plate) so you can look out for it.

Obviously it depends on the back end booking/scheduling system used, but if taxi firms can do it, it shouldn't be beyond possible. It would have obvious benefits for the users - less waiting/uncertainty, but would likely also pay itself back in time gained for the drivers from people being ready & prepared on time.

> A permanent feedback mechanism

Suggested by JohnGreenaway

Issue:

This site is a great idea, but it's fairly transitory. Quite a few things come up during treatment that would be nice to suggest to someone, but it's not really obvious who to speak to. The nurses/doctors are generally pretty busy, and a lot of the possible suggestions are more about process, so more for the managers. And a lot of the issues is cancer care a cross-disciplinary anyway. So as a patient they isn't an obvious place to make suggestions to (presumably hence the need for a project like this current site!)

Suggestion:

A more central feedback site/address/postbox for cancer care, but permanent. Though who it goes to/funds it might take some thinking.

> Focus on the prevention and early detection of skin cancer Suggested by Sharon H

There is little focus on the prevention and early detection of skin cancers. We know that there are >13000 cases of malignant melanoma in the UK and more than 2000 deaths despite 86% of cases being preventable! Melanoma is the 2nd most common cancer in 15-34 year olds and now the 5th most common cancer in the UK. Cancer Research UK note that over the last thirty years, rates of malignant melanoma in Great Britain have risen faster than any of the current ten most common cancers and incidence rates have increased more than fivefold since the mid 1970s.

More needs to be done to educate the public on how to prevent skin cancer in the first place i.e. sun awareness in schools etc, general media/public health campaigns and how to detect skin cancer early. Just one episode of sunburn every 2 years can triple your risk of developing melanoma! There needs to be a much greater public health message and investment into this largely preventable cancer. The Slip, Slap, Slop campaign in Australia is a great example of this.

> Information sharing across the service Suggested by Dorothy E

When I was undergoing chemotherapy and radiotherapy, I had to contact my gp out of hours service. Whilst they were helpful and professional they didn't know anything about me or my treatment plan and were working 'blind' without access to notes. Why can't GPs have access to the record system so that they know something about your treatment, or better still couldn't they have access to a specialist opinion during weekends? through my work in the nhs I am aware that Scotland have a dedicated helpline linked to NHS 24 service for patients undergoing chemotherapy or radiotherapy to provide this backup. Couldn't Wales do the same?

> Improve information for newly diagnosed cancer patients Suggested by DavidClinch

I was given my diagnosis in five minutes flat and then the nurse spoke to me in a busy corridor in the hospital, she gave me a booklet and with that I was allowed to go home and worry. The waiting and the unknown are incredibly stressful and completely unnecessary. Patients should have secure online access to their own "treatment pathway" so they can better understand what is going to happen next, what the possible outcomes will be and most important of all, how long they are going to have to wait for the next appointment/treatment. This patient interface should sit on top of whatever system is in place (assuming cancer care in Wales has a digital joined up system of course!), it could also include any number of links relevant to their particular disease as well as providing a contact/query function.

> Respect Patients' Input in Consultations

Suggested by AnnieMulholland

I've been involved in the Velindre Cancer Centre Patient Centred Consultation on the future of cancer services in SE Wales and I'm just totally perplexed by the process that has been adopted. I don't feel patients have been properly consulted so far and I hope this will change. I attended the first event and found myself to be the only patient amongst a delegation of staff, allied workers, charities and government officials. At that event the delegates were told a new model was being proposed based on the premise that patients 'wanted treatment nearer their homes'. The proposed model was described as a 'cancer village' with outreach centres dotted round a central provision. One breakout group at the event was asked to consider the challenges of delivering treatment in outreach centres and they identified staff isolation, transport issues, and poor access to training as major factors for consideration. As a patient I can think of many others but I wasn't part of that group and I wasn't asked to make a comment. I was unnerved by the assumption that patients wanted treatment nearer their homes given patients had not been consulted and hoped the topic would be discussed at the subsequent Patient Consultation Events but it wasn't. At the patient event one delegate raised the topic and said from their personal perspective they would not welcome treatment in small outreach centres and this view was endorsed by other patients. At no point in the patient consultative event was the topic broached as a formal part of the day's discussions. I have asked the Velindre Consultation Team whether there's an evidence base for their assumption that patients want provision nearer their homes but have not yet received any reassurance that any sort of research has been undertaken. It's worrying if the basis of the recommendations for the future of cancer services in SE Wales are not based on some sort of evidence that the model is what patients want or will use. I have now received an email from the Velindre Communications Team for the Review of Cancer Services saying nearly four hundred people took the time to come along and contribute their thoughts on how we should improve cancer services in south east Wales, and listing some of the key messages that came out of the events.

One key message the Velindre Cancer Centre claim they have received is that there is 'strong support for Velindre providing more services closer to home.'

This statement is completely untrue. The staff raised concerns, and the patients haven't been consulted at all. There is no Strong Support for such a proposal though if patients and staff were properly consulted it may be the notion would receive support and a survey could identify the most appropriate locations for outreach centres.

I resent wasting my time attending a 'consultation event' that has been rigged. I thoroughly resent the elaborate pretence at a patient consultation when there clearly has been none. I find it patronising that senior figures think they can get up on a public platform and tell patients what patients want when it is obvious that patients have not been consulted. If agencies and authorities want to consult with patients on cancer services, and that includes this current consultation, may I make the reasonable request that they do so in an open, honest, respectful and professional manner that gives due consideration to patient input and intellect.

> Joined up patient information

Suggested by ShanEv

Need single data source containing all relevant information, this would save errors and money. For example whilst en route to hospital for my pre med I was calling the breast screening unit to cancel annual appointment which had just been issued as had been diagnosed with cancer a couple of weeks earlier.

Similarly having been to my GP following finding a lump had to really push to get a secondary care appointment, if I hadn't previously had cancer experience would have waited far too long.

> Sometimes it's the simple stuff,

Suggested by ShanEv

Having recently been through my third cancer diagnosis some of the simple things would make life much easier. For example bringing care locally wherever possible. I had a drain in for 19 days post surgery, once I had left hospital I, and my driver, had to make a round trip of over 40 miles 3 or 4 times a week to have the bag changed. Why couldn't this have been done either at local hospital (not a district general hospital) or my local surgery? I could even have changed it myself and emailed photo/measurement in if needed. Making patients and their families spend hours and £££ on these types of journeys is unnecessary and delays recovery. Whilst I was still in hospital I complained about having to go back to have the bag changed and suggested local solutions, the response was to threaten to keep me in hospital for another fortnight until the drain could be removed.

> Claiming benefits could be clearer and fairer

Suggested by Jayne Mason

Many people diagnosed with cancer do not realise what benefits and help is available for them, and they are also too ill to complete lengthy claim forms or to pursue any claims.

> Text / Phone patients to alert them in advance of long delays to appointment times

Suggested by DavidJohnSutherland

If there are delays with appointment times then why not text or phone the carer/patient in advance advising them that there is a one or two hour delay and they can make a choice as to how to manage their time.

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