
Patient Voice in Cancer Research (PVCR) & National Cancer Research Institute (NCRI) UK

Putting cancer patients at the centre of cancer research

Dragons Den Event:

- Recommendations on Research Initiatives & Proposals
- Informed by patients and carers

Tuesday 25th February 2020 - Galway Bay Hotel, Galway



Contents

- 1) Cancer research proposals/ projects by table
- 2) Dragon/ participant recommendations
- 3) Summary notes

Table 1

To develop an online hub providing information currently unavailable for cancer patients and survivors. (1 of 2)

1

Problem statement

- The Irish Cancer Society published a document titled ‘The unmet needs of cancer survivors in Ireland, a scoping review 2019’. This highlights the extent to which the needs of people living with and beyond cancer are not being met;
- Specifically people need greater access to support services and need more appropriate information support;
- There is an information deficit, for patients to participate in any decision making they require adequate information.

2

Scale of demand for information

- There are almost 175,000 people in Ireland living with or following a cancer diagnosis. Hence the demand for information services is big.

3

Proposed solution for Dragon consideration

- The project is working to produce an ‘E-Health Directory which serves as a credible authentic information hub’;
- The ‘E-Health Directory’ would contain validated fact based information and links to specialist services and information sources that provide advice to patients;
- The working group through patient focus groups will determine the types of information gaps that exist and build the **E-Health Directory** with the aim to fill the gaps;
- The group will research on-line tools in other countries;
- The working group will test a prototype with focus groups.

4

Expected value of an ‘E-Health Directory’

- The ‘E-Health Directory’ gives patients a level of independence and allows patients to look for particular advice;
- The patients can use the E-Health Directory to find advice on services and book appointments;

The path for developing an ‘E-Health Directory’

Patient ideas & global good practice		Initial concept Design solution	Build content Input from experts
Patient focus group	Online tools in US, Australia, Europe		

Questions

1. Understand the patient experience in transitioning from inpatient to outpatient services?
2. At what points in the treatment journey are patients provided information, before surgery, post surgery, at chemo, at radiation, etc.?
3. How do patients find information and what sources do patients use?
4. What would have being beneficial when going through treatment that might be of benefit to future patients?



Information dissemination – build an E-Health Directory for patients to use with access to advice services / links to reputable services

Table 1

To develop an online hub providing information currently unavailable for cancer patients and survivors. (2 of 2)

Insights sought from patients

1. Suggestion on types of information or methods of getting information that might benefit future patients
2. Ideas for better managing the transition from inpatient to outpatient

Question	Patient response
What services are top of mind?	<ul style="list-style-type: none"> ▪ Cancer Care West, Irish Cancer Society, Barretstown, St. Vincent's come to mind ▪ MacMillan course is considered dated and poorly delivered. MacMillan is UK focused and not necessarily transferable to Ireland
Are patients well informed on services / supports?	<ul style="list-style-type: none"> ▪ No, in general patients are not told by the clinicians. It may be the nurse who advises on the support services ▪ Patients feel alone and no formal process for advising patients of support services
Where in the treatment path is information most lacking?	<ul style="list-style-type: none"> ▪ The 1st time on experiencing side-effects ▪ Because of the shock it is difficult to retain & process the information from clinicians ▪ No discussion on fertility or options to harvest/freeze eggs, no choice given ▪ Not routinely advised of the side-effects
Do you know if the information you access is trustworthy?	<ul style="list-style-type: none"> ▪ Patients have no idea if it is correct ▪ Patients check a number of sites and see if the messages are reasonably consistent

Patients feel they are not supported and feel that advice is limited.

They especially feel vulnerable when side-effects occur as they have no guidance or warning of what to expect.

This is psychologically testing for individuals.

A dilemma for patients is when the oncologist provides advice it can be difficult for the patient to process the information.

A reference book would be useful, patients could refer to this book or master guide as required and it could serve as an official guide.

A sense of isolation in lacking information and not sure where to get answers

Problem is you are **not told of the side effect by the oncologist**. The side effects can be horrific and if you are not warned you have no idea of what is normal or what to expect

According to my husband the doctor did tell me the stage and grade **but my head was gone**

The only place you get information is from **speaking to other patients**, it can be confusing

At the time of diagnosis it is scary, with Prostate you have to **deal with side effects** like erectile dysfunction

Too much information can be bad but if you have a book you can go back and refer to it

I had to do things off my own bat. It is up to you to find the information, you are **on your own**



Information dissemination – build an E-Health Directory for patients to use with access to advice services / links to reputable services

Table 2

To develop a patient involvement plan for precision oncology Ireland (1 of 2)

1

Problem statement

- Precision medicine uses the patient's unique genetic data to inform the treatment path of an individual's cancer;
- This essentially is personalised medicine;
- Precision Oncology Ireland (POI) is a consortium of 5 Universities, 6 cancer research charities and 10 companies who are collaboratively working to develop diagnostics and therapeutics for personalised cancer treatment;
- POI is collecting data and DNA profiles to build data methods to help develop better diagnostics & drug discovery

2

Impact of the POI initiative

- POI is working to develop new diagnostics and therapies that will benefit cancer patients;
- Over the next 5 years the POI has committed funding of c.€11.9m and needs to prioritise the drawdown of this funding on the most appropriate projects and focus areas;
- It is considered appropriate that the **voice of the patient** be used as an input into the prioritisation of this research effort.

3

Discussion for Dragon consideration

- POI want to **involve patients in determining the patient needs** regarding **projects and topics** which should be **prioritised**;
- The POI wants research to be aligned to the patient need
- The POI has a draft **patient involvement plan** on how patients can input to the overall POI work programme

4

POI ambition and purpose

- The POI wants patients to be involved in a meaningful way
- The POI recognises that patients and their families are experts in the living experience of cancer and are well qualified to identify needs & problem areas that require the research community to find solutions
- The POI wants to use a Patient Involvement Plan that is effective and makes a positive difference

Questions

1. **How can patients contribute to the POI programme?**
2. **Any suggestions from patients in response to the initial Patient Involvement Plan?**
3. **How could patients work with the POI?**
4. **What format is most useful for patients and POI to work together?**
5. **What is a reasonable time commitment from patients?**



POI is a collaboration between universities, cancer charities and companies working on a search for new treatments. The POI wants patient input.

Table 2

To develop a patient involvement plan for precision oncology Ireland (2 of 2)

Insights sought from patients

1. Patient input into a "Patient Involvement Plan"
2. An informed approach where Patients can work with the POI to ensure research is centred on the patient need and that the appropriate prioritisation of research projects happens
3. Input from patient on the needs of patients regarding the research effort by the POI

Patient reaction to the draft Patient Involvement plan

1. Very positive with unanimous agreement it was good;
2. Patients are very willing to be involved but want more than a token role

Points of clarification:

- In broad terms the range of projects are already scoped but the patients can help refine some aspect of a project scope or patients can help agree a prioritisation schedule;
- There is opportunity for the patient voice to steer a project in a particular direction and these tweaks can add value;



Patients are supportive of a Patient Involvement Plan.

Patients want a meaningful role & want to contribute in a positive way.

There should be patient representation on the governance board.

Patients support the use of public meetings as a way to build awareness and communicate key messages.

The POI and Patients should facilitate a community type engagement, i.e. the POI should go out to the community and setup patient groups

Important that researchers in POI have suitable training to facilitate patient groups and manage what may be emotive discussions for patients

Out of pocket expenses should be paid and should be recognised in the budget as part of the grant application



Patients made clear that they don't want a token role and be seen as ticking a box



Any out of pocket expenses for patients should be covered. Suggested that out of pocket expenses should be factored into the grant application at the outset. Emphasised that projects should be properly budgeted at the start and the expenses not omitted and picked up as an after-thought later



Patients want to be properly involved and have an engaging role in working with the POI



If training is provided it should be kept relevant, the experience with IPPOSI training and quite a lot of the content was irrelevant.



Any input from a patient on a research project should be acknowledged



POI is a collaboration between universities, cancer charities and companies working on a search for new treatments. The POI wants patient input.

Table 3

To Improve awareness of cancer associated Thrombosis [CAT] (1 of 2)

1

Problem statement

- An implication with cancer is the risk of developing a blood clot also known as 'cancer associated thrombosis';
- Circa 1 in 5 cancer patients are likely to get a blood clot but the condition is under-reported and rarely discussed;
- The problem with clots is when they travel to the lungs they can stop the blood flow resulting in pulmonary embolism which may be fatal.

2

Importance of being aware

- Typically if a clot is detected early it can be treated. However if the clot is ignored then the outcome can be fatal;
- Therefore it is important for cancer patients to be vigilant and look for early signs of a clot so fast action can be taken.

3

Proposed action for Dragon consideration

- This project is working to ensure all cancer patients are informed and aware of the risks of Cancer Associated Thrombosis;
- The outcome of the project should be that cancer patients know the signs of a clot and know the steps to take and do apply FAST action;.
- This project should complement / leverage the work being undertaken by Thrombosis Ireland.

4

Related work and advocacy body

- Thrombosis Ireland is a registered charity established by patients in 2016 to raise awareness about thrombosis
- Thrombosis Ireland provides information and education materials

Questions

1. **As a patient are you aware of cancer associated thrombosis (CAT)?**
2. **Do you know what signs to look for in recognising a clot and are you aware of the need to act fast?**
3. **Is the Blood Clot Aware Card effective? How could it be improved?**
4. **Do cancer patients have the right information?**
5. **How best can information be disseminated to cancer patients?**
6. **What forum is best for providing information to cancer patients?**
7. **What type of communication is best and when should the messages be provided to patients?**



Information dissemination – need patient input on how best to communicate the risk of cancer associated thrombosis, what methods are best

Table 3

To Improve awareness of cancer associated Thrombosis [CAT] (2 of 2)

Insights sought from patients

1. Ideas for information cards and posters;
2. Ideas for campaigns to raise awareness on CAT;
3. Capture stories on some personal experiences of CAT;
4. Any suggestions from patients that can help improve CAT awareness and thus achieve better outcomes

Important messages on Thrombosis

1. Thrombosis can be prevented in 50% of cases;
2. Typically 1 in 5 patients will experience thrombosis within the 1st three months after cancer diagnosis

Level of awareness among the patients at the table

- Patients **not aware** of cancer associated thrombosis
- Patients were aware of the link between long haul air flights and thrombosis;

Patient response to alert cards and leaflets

- Patients found the visual aids to be effective
- Patients said the content and layout of cards was good;
- Patients suggested the cards should be gender neutral
- The cards should have more specific detail on the pain level
- The cards should have impact and patients suggested the cards "should shock with facts"

The cards should enforce messages on the level of pain experienced.

The cards should shock with facts and therefore carry impact & thus create a call to action type response.

Cards should provide tips on how to avoid thrombosis such as small walks, staying hydrated, regular movement, no smoking.

Patients said timing of information on thrombosis risk should be early and ideally at the treatment planning phase.

Advice to patients should be given by either the clinician or the nurse

Patients should be given an information booklet at the time of diagnosis

✓ Patients want to know why the risk of thrombosis is high in the 1st three months after the cancer diagnosis

?

Patients would like to receive an information booklet pack. Even if they are overwhelmed with all the information at least they can take the booklet to read and digest in their own time.

✓ Patients want to know why cancer has an increased risk of thrombosis

✓ The person best placed to give advice on thrombosis risk should be the clinician or the nurse



✓ Possible that patients are given advice but don't link it to the risk of thrombosis. Patients do recall being told to move regularly and to take short walks



Information dissemination – need patient input on how best to communicate the risk of cancer associated thrombosis, what methods are best

Table 4

ImmunoCell - Targeted treatment to improve ovarian cancer outcomes (1 of 2)

1

Problem statement

- Ovarian cancer symptoms are not easily identified and most women present with advanced ovarian cancer;
- 5 year survival rates can be less than 30%;
- Current treatment via injection gives rise to issues with managing **sufficient concentration** levels while **avoiding toxicity**;
- Delivering chemotherapy directly into the abdomen via catheters has been trialled but difficulties are encountered with **blockages** and it **causes discomfort for patients**;

2

Recent development

- A new device called an ImmunoCell has been developed;
- This is placed in the abdomen during tumour resection surgery and attached to a port on the skin;
- This can be placed directly over the tumour site and medicines can be injected through the port in the skin and travel directly to the tumour site
- It is **easy to unblock** should a blockage occur

3

Proposed solution for Dragon consideration

- The big advantage of the ImmunoCell is instead of injecting traditional chemotherapy medicines, **natural killer cells** can be used;
- These natural killer cells are part of immunotherapy treatment;
- This treatment can kill cancer stem cells left behind after the tumour resection & thus prevent recurrence of ovarian cancer

4

2 possible designs for the device

- One design allows broad delivery of therapy to the entire abdomen;
- The 2nd design allows delivery of medicine to the specific tumour site;

Questions

1. How would a person feel about having a device implanted in their abdomen?
2. Would people worry that normal movements might affect the device?
3. Would they rather for the device to be left in or taken out at the end of the treatment?
4. Has anyone have had experience of receiving chemotherapy directly to the abdomen and how was the experience?



The ImmunoCell is a technology which can inject immunotherapy medicine directly to tumour site. It is easy to unblock & is more comfortable for the patient

Table 4

ImmunoCell - Targeted treatment to improve ovarian cancer outcomes (2 of 2)

Insights sought from patients

1. How do patients feel about having a device implanted in the abdomen;

Limitations with the current treatment approach

1. It is difficult to get the balance between the sufficient **medicine concentration** and **toxicity** side effects;
2. Targeted delivery is currently via a catheter which is **subject to blockages**;
3. The catheter causes **extreme discomfort** to patients;
4. Patients need to be turned every 15 minutes after treatment to help dispersion.

Patient concerns with a device implanted

- Is there a risk of infection and are there issues with bleeding?
- What size is the device?
- Does the device need to be flushed?
- How does the device work and how is the medicine delivered?
- What attaches to the port?
- Are there multiple reservoirs in the tumour area and does one port feed all the reservoirs?
- Is it possible to show patients how the device operates before a decision on implantation is taken?

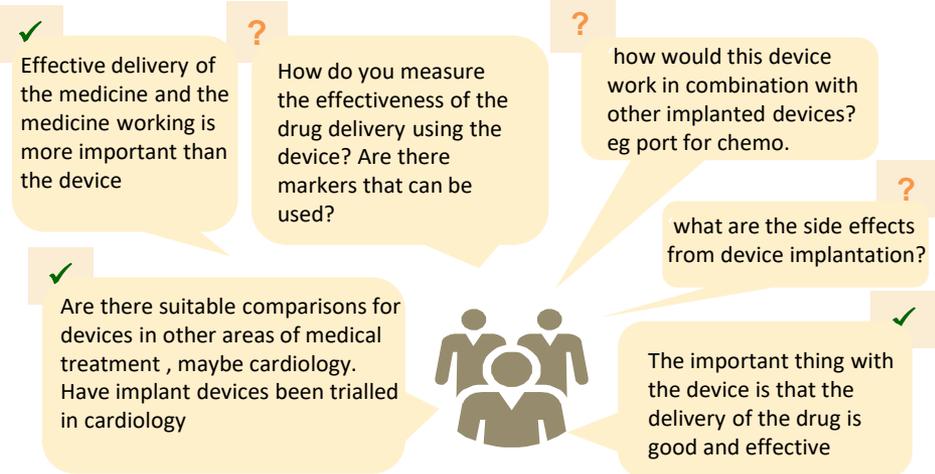
A concern among patients in using an implanted device is the size of the device and the extent of discomfort about a device in the abdomen

However a sense that if the drug delivery is effective then it outweighs any discomfort associated with the implantation

Some interest among patients in checking if there are suitable comparisons from other medical implants in areas such as cardiology

Also patient interest in how the medicine attaches to the port and how it works in practice

Patients interested to know about side effects such as bleeding or infection risk with a device implanted



The ImmunoCell is a technology which can inject immunotherapy medicine directly to tumour site. It is easy to unblock & is more comfortable for the patient

Table 5

Coping skills for a genetic mutation diagnosis [BRCA 1 or 2] (1 of 2)

1

Problem statement

- Mutations in genes BRCA 1 or 2 can increase cancer risk, BRCA 1 mutation can increase breast cancer risk by 60% - 90%;
- BRCA 2 mutation can increase breast cancer risk by 45% - 85% and ovarian cancer by 10% - 30%;
- There is significant psychological distress in learning of a BRCA mutation diagnosis with women advised to undergo surgery in addition to impacts across a range of areas

2

Challenge associated with the problem statement

- In Ireland to date there has been **little research on the psychological impact** of a BRCA mutation diagnosis for women

3

Proposed response to the challenge

- To do **research into the experience** of those who receive a BRCA mutation diagnosis and **develop an online psycho-educational programme**;
- Provide material which helps women adjust to a BRCA mutation diagnosis

4

A three part approach being taken

- A **review of existing research** on interventions regarding the psychological challenge for people who learn of a genetic mutation. This review will seek to assess the methods used and the outcomes;
- A series of qualitative **interviews with women** into their experience on learning they were carrying a genetic mutation;
- Based on the **findings** from the interviews and the review of existing research an **intervention will be developed**. The idea is that this new intervention will benefit from the findings of the previous interventions and the experience of women

Questions

1. **Is an on-line medium useful and appropriate for women?**
2. **Any recommendations for the type of content within an on-line information programme**
3. **Any recommendations on the format / layout for an on-line information programmer**
4. **Feedback on a proposed recruitment leaflet to attract candidates for the qualitative interviews**
5. **Any views on choice of language and use of emotive terms such as 'diagnosis', 'patient', etc.**



Improve the psychological support available to women who are carrying a BRCA gene mutation & establish intervention to improve the coping ability

Table 5

Coping skills for a genetic mutation diagnosis [BRCA 1 or 2] (2 of 2)

Insights sought from patients

1. Any prior experience with on-line support
2. Any views on psychological interventions
3. Any ideas on how best to gather/capture patient input

Some recommendations on language

1. Suggest avoid the term 'patient', instead the reference should be 'BRCA mutation carrier'
2. The term 'previvor' was considered very American and also misleading as only some may opt for surgery and those who opt for surgery may still experience cancer and may not survive cancer

Suggestions for qualitative research recruitment

- Understanding of the terminology is poor, however should refer to the persons as "BRCA mutation carriers";
- Concern that family members are often divided with some wanting to be tested and others not wishing to take the test, hence stigma and psychological impact for both;
- Some people may have a fear of being tested & the result;

Suggestions for the on-line education platform

- The option to test for BRCA mutation is new with awareness levels and knowledge relatively low, hence need to provide easy tips such as 'where to go to be tested';
- The site to provide guidance on **discussions between family members**, tips to facilitate conversations among members;
- Maybe a **liaison person** to assist families

Some people experience a guilt with cancer.

Discussing 'BRCA mutation' among family members can be difficult.

Some family members may have a fear of the test and fear the result.

Communication is poor, there is no guidance or tips available on how to discuss BRCA mutation with family members.

Standard of care varies across the country, geneticist on some teams only.

Suggest that a resource tool would include tips on how to facilitate discussion within the family.

Given that BRCA mutation awareness and understanding is low, the on-line tool should serve as an easy helpful set of tips.



Guilt among family members who do not carry the BRCA Mutation while other members carry the mutation and ask 'why them and not me'



Maybe a designated person can support a family in a similar manner to the type of support families may receive when engaging with addiction services. A designated person would assist with psychological support.

Irish people find it hard to confront a difficult issue, there is a sense that 'what you don't know won't hurt you'



May feel a guilt with a cancer diagnosis and feel bad telling family. But yet do not express their sense of guilt to family members. People speak of a "sense of guilt" at bringing this cancer onto the family



'It is hard to tell family members you carry the BRCA Mutation'



'Coping with complex emotions requires a deep intervention'



Improve the psychological support available to women who are carrying a BRCA gene mutation & establish intervention to improve the coping ability

Table 6

Home based device for fluid management in late stage cancer (1 of 2)

1

Problem statement

- 15% of cancer patients experience fluid build up near the lung;
- The fluid build up results in chest pain and breathlessness;
- The current method for patients to manage fluid at home is through **a tube device placed into the chest**;

2

Recent development

- NUIG are working on an alternative to the current 'tube device into the chest'. The focus is to develop a new device with patient input and ensure the design is patient centric;
- The NUIG team want to include the patient voice in the design

3

Seeking input and consideration from Dragons

- The innovation is a user-friendly device which can be used in the home to assist people drain a build up of fluid in the chest;
- This innovation will be superior to the current tube device;
- This new device will use **design principles based on patient experience** of the existing device;
- The new device will try to overcome the problems which patients voice as negative when using the current device;
- The team wants to fully understand the current pain points that patients experience when using the tube into the chest

4

The type of feedback sought from patients

- Describe the experience with draining devices in palliative care;
- Describe the experience of draining fluid in the home setting;
- To support the capture of research feedback a short questionnaire is proposed, this ensures no one voice or opinion dominates a group discussion. The survey ensures all participant experience is captured;
- A visual presentation of the current tube device is presented for participants to identify the pain points and nuisance issues in using the current tube device, an open discussion to identify improvements

Questions

1. **What factors matter to the patients?**
2. **What design features can improve the quality of life for the patient and the carer?**
3. **Suggestions on how the current device can be made more user friendly for patients**



Intention is to design an alternative to the current fluid draining tube device which is easier for patients to use at home

Table 6

Home based device for fluid management in late stage cancer (2 of 2)

Insights sought from patients who:

1. Have past experience of using a tube into the chest to drain fluid;
2. Carers who have perspectives on managing fluid build up in the palliative care setting;

Challenges with the current method for draining fluid

1. Patient is not independent, the patient requires support to drain the fluid;
2. Installation of the tube requires an **invasive tunnelling** procedure;
3. The external pipe & valve is **large and cumbersome**;
4. The wound needs to be dressed constantly;
5. Because the wound needs to be kept dry it reduces the range of activities possible for the patient;
6. The dressing may be required for between 3 to 12 months;

Key functional features for a new device:

- Ability to **self-drain** daily;
- Avoid the need for a large pipe by designing a **small port** for under the arm which would be **water-proof** (allowing patient to swim or shower);
- **Avoid the need for a surgical tunnelling** procedure;

A good device should be able to self-drain daily.

A water-proof design of the port under the arm, which would negate the need for a large pipe and dressing.

Water-proof design allows patients continue with many daily activities such as swimming or showering.

Avoid surgical tunnel procedure when installing the new port, minimises patient discomfort.

Don't underestimate the requirement for adequate training of clinicians, patients and care providers



Need to **train the patient** to use the device properly to self-drain



Ability to reduce the time with the device in situ to 30 days due to an alternative approach developed by the team to speed up healing to remove the need for fluid draining



Need to **train clinicians** on installing the device properly



Need to train the care provider in using the device with the patient



Management of chemotherapy induced pan-cytopenia (1 of 2)

1

Problem statement

- Pan-cytopenia occurs when someone has low counts of all three blood cells – white blood cells, red blood cells and platelets.
- Chemotherapy can cause '**neutropenia**' a condition marked by a **low level of neutrophils** (a type of white blood cell);
- A low neutrophil count results in a poor immune response to bacterial infections. The immune system is greatly impaired;
- Adverse cases result in Febrile neutropenia (high temperature). In the US annually c.60,000 patients are hospitalised with a mortality rate of 21%.

2

Challenge of Febrile Neutropenia (FN)

- Detection is late and not until the patient presents in the hospital with high fever & the FN is diagnosed via blood tests
- FN requires rapid treatment with antibiotics to prevent sepsis;
- The patient can't self monitor at home.

3

Proposed solution for Dragon consideration

- The innovation is a test kit 'Neutro-check' which means the neutropenia can be **detected before a fever** develops and before the patient presents in a hospital;
- The patient can '**self-check**' at home;
- The advantage is the patient can be **treated as an outpatient** with targeted antibiotics and growth factors

4

Nature of the project and key benefits

- This innovation is an easy to use monitor, slightly invasive;
- The Neutro-check functions by checking the physical properties of the blood with no need for biochemical preparation and is therefore simple, reliable and accurate;
- A validation of the Neutro-check found a specificity of 94% when compared to results from a traditional blood cell counter;
- The Neutro-check device is similar to other home devices such as the glucometer;
- In time the Neutro-check could be used for other tests such as red blood cells, platelets.

Questions

1. **Do patients have information on the side-effects of chemotherapy?**
2. **Are patients familiar with the risk of cytopenia from chemotherapy?**
3. **Are patients happy with the current approach for managing cytopenia?**
4. **What additional information is required by patients?**
5. **Would the patient use a home device to monitor bloods?**



Diagnosics - home test device to allow patients detect early for neutropenia before the onset of high fever and the need for hospitalisation

Table 7

Management of chemotherapy induced pan-cytopenia (2 of 2)

Insights sought from patients

1. Would patients use a home device to monitor their bloods following chemotherapy?
2. Is it useful for patients to self-monitor at home and thus reduce the risk of developing infections?

Key benefits of Neutro-check home device ✓

1. Chemotherapy can kill off blood cells and low blood cell count can result in neutropenia which puts the patient at risk of serious infection. A home device helps patient self-monitor, detect early & reduce acute risk;
2. Neutropenia can result in sepsis, acute situations may need to be managed within a 2 hour window, thus using a home device allows for early intervention before the onset of a crisis.
3. Neutro-check reduces the need for hospitalisation

Patient reaction to Neutro-check home device:

- a) Patients aren't aware of neutropenia & have no knowledge neutropenia may occur as a side effect of chemotherapy;
- b) There needs to be better communication of side-effects from the start of the diagnosis right through the treatment;
- c) Patients recognise the value & benefit of the Neutro-check
- d) Patients believe adding functions to the Neutro-check such as heart rate and temperature sensors would be really useful

Patient awareness of neutropenia is low and they have very little guidance.
 Patients have little information apart from to check their temperature.
 Patients need much more comprehensive information on side-effects.
 Patients should be advised of both the short term and long term risks.
 The Neutro-check is a **great idea and highly valued** by the patients;
 Additional functions such as heart rate & temperature sensors are good

✓ The availability of a device would give patients control which is considered valuable

? Awareness among patients of neutropenia is very low. Patients are given little guidelines apart from being advised to buy a thermometer and to regularly check on their temperature. The guidance being if the temperature is high to go to the hospital. Patients have no idea the time window is as critical as 2 hours

✓ Patients welcome a device which gives a sense of control to prevent problems and complications

✗ Patients are not told about side effects such as thrombosis, mouth ulcers, malnutrition, or neutropenia. The only guidance seems to be to take anti-sickness tablets.



✗ Patients feel they are kept in the dark and feel they need to do their own research on the internet

✗ Never told about long term risk such as infertility



Diagnostics - home test device to allow patients detect early for neutropenia before the onset of high fever and the need for hospitalisation

SmartAblate - a device to improve lung cancer treatment (1 of 2)

1

Problem statement

- Presently surgery is the main treatment option in lung cancer, with few other alternatives available;
- Only 15% of lung cancer patients are suitable for surgery;
- Surgery is painful with difficult after-effects;
- The main alternative to surgery, stereotactic body radiation therapy (SBRT), is only available in certain centres in Ireland.

2

Recent development

- Advances in lung imaging technology allow for lung tumours to be biopsied using a catheter via the trachea;
- Imaging technology can direct the catheter to the correct location for a biopsy to be taken.

3

Proposed solution for Dragon consideration

- SmartAblate investigates the potential to use the catheter to deliver '**microwave lung ablation technology**' to treat the cancer;
- Microwave lung ablation technology uses microwaves to heat the tumour and a small portion of surrounding tissues to high temperature (>55°C) to kill the tumour cells;
- A challenge is to accurately position the catheter and the ablation probe in the correct position centred in the tumour and not kill healthy tissue. The imaging technology is critical.

4

Nature of the project and key benefits

- SmartAblate project tries to overcome risks with inaccurate positioning of the ablation probe;
- The ablate project is assessing the use of sensors and the use of sensor data so probes can be repositioned for optimal treatment;
- Also potential for sensor data and machine learning to further improve location accuracy and reduce damage to good healthy tissue.;
- Improved treatment path for patients;
- Reduction in the need for lung surgery;
- Reduced in patient care for patients.

Questions

1. **What is the patient experience of current lung cancer treatment?**
2. **What is the quality of Life for patients post lung surgery?**
3. **For patients not suitable for surgery, how can SBRT treatment affect their lives in terms of tolerance, the severity of the treatment and number of treatments, quality of life during & after treatment?**
4. **Patient view on microwave lung ablation via a catheter?**



Diagnostics and imaging technology together with machine learning to better improve lung cancer treatment for patients

SmartAblate – a device to improve lung cancer treatment (2 of 2)

Insights sought from patients

1. How invasive are the current treatments?
2. Why do people choose a particular treatment path?
3. What factors influence a patients decision on a treatment path?
4. How could microwave lung ablation treatment be designed to be a superior choice for patients and overcome the disadvantages of other treatments?

Key benefits of microwave lung ablation ✓

1. Tumours can be biopsied, staged and treated in the one session;
2. Shorter time in hospital;
3. Faster recovery time;
4. Reduced risk of infection;
5. Reduced scarring.

Main patient concerns with microwave lung ablation:

- How is the **success of treatment assessed**, and what follow up visits /tests are required?
- If the microwave lung ablation treatment is not successful can **other treatments be still administered** / available?
- What patient support is available?
- Any counselling service provided?



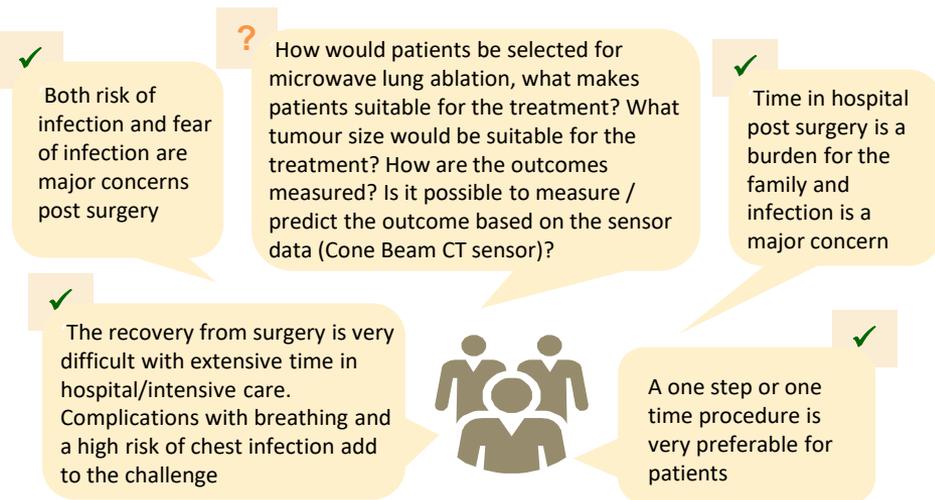
Patients are **positive regarding microwave lung ablation treatment** and recognise the benefits.

Long hospital stays are not satisfactory and place a burden on family and carers.

The risk of infection post surgery is problematic.

Patients see scarring as a stark reminder of the illness.

Patients do not like anaesthetics and prefer sedation.



Diagnostics and imaging technology together with machine learning to better improve lung cancer treatment for patients

Table 9

Smoking cessation for cancer patients in Ireland (1 of 2)

1

Problem statement

- Cigarette smoking causes a number of different cancers;
- Patients may not know that continuing smoking after treatment increases the risk of the cancer returning as well as a new cancer starting;
- Hence the outcome for cancer patients is not as good if patients continue to smoke;
- Studies have shown that people who stop smoking have a better chance of living longer with a better quality of life.

2

The challenge

- Studies indicate that **uptake of 'smoking cessation services' is in decline**, while **smoking rates can be high** among cancer patients and their relatives;
- A cancer diagnosis may trigger people to quit smoking

3

Proposed research initiative for Dragon discussion

- Research will be undertaken with cancer patients attending SVUH, the Mater Misericordiae University Hospital, and St. Luke's Radiotherapy Hospital;
- The research will explore reasons for a low uptake of smoking cessation services among cancer patients;
- The research will look to identify factors that may motivate individuals to quit smoking;
- The intention is to involve lung cancer, cervical cancer and breast cancer patients in the research

4

This research initiative has a number of objectives

- Establish an understanding of why smokers may be reluctant to avail of a smoking cessation service;
- Use research findings and current patient attitude to inform an action plan which can effectively address and overcome the current barriers to smokers wanting / trying to quit smoking;
- Raise awareness that continued smoking increases the risk of cancer returning or new cancers starting;
- The final outcome is that hospital and community based resources can help people with cancer to quit smoking;

Questions

1. **Suggestions from the Dragons on the type of questions which should be included in a patient interview**
2. **As a smoker or former smoker any guidance regarding the type of language or terminology that is appropriate for a interview questionnaire**
3. **Is it appropriate to ask lung cancer patients at the diagnosis to refer family members to a cancer cessation service**
4. **Any suggestions on how best to recruit people to participate in the research**



Research into understanding barriers to the uptake the 'smoking cessation services'

Smoking cessation for cancer patients in Ireland (2 of 2)

Insights sought from dragons

1. How best to recruit patients to participate in the research
2. What is the most appropriate time to contact patients regarding being involved in a research study

Factors to test which may influence people's attitude

1. Correlation between smoking cessation and a positive outcome post treatment
2. The risk that patients who continue to smoke may increase risk of cancer returning or new cancer starting
3. Risk that on diagnosis people who previously quit smoking may relapse
4. Need for campaigning activity to maintain a focus on health risks associated with smoking
5. Need a positive focus and guide people towards initiatives that work such as acupuncture, nicotine replacement treatment (NRT), etc.

Findings based on the Dragon discussion

- Suggest that patients be **offered a choice** between doing an interview during treatment or waiting till after the treatment
- Suggest that participants in the research be split between people who **recently quit** and those who **quit in the past**
- Include people who may **have quit smoking but relapsed**;

Recruitment of participants for the research should have a balance of people who recently quit smoking, people who may have quit a long time ago and people who quit but relapsed

In terms of people currently in treatment the suggestion is that they be given a choice if interested to take an interview during treatment or wait till after the treatment

The interview diagnostic should explore some negative aspects such as emotional trigger of guilt & shame, the fear of not being cured or the threat of the cancer returning in the future

The diagnostic should consider positives such as a better quality of life post quitting & willingness to try successful cessation programmes e.g. NRT, Acupuncture



Any research **requires the interviewer to have good interview technique** and be cognisant of the interviewee's situation. If the interviewee is beginning to feel uncomfortable the interviewer should stop probing



In probing patients during interviews explore **the role of family support and other support** systems



Explore views on vaping



Explore the **feeling of shame or guilt** with smoking and knowing the health warning



Research into understanding barriers to the uptake the 'smoking cessation services'

Table 10

Impact of non muscle invasive bladder cancer on quality of life (1 of 2)

1

Problem statement

- Bladder cancer is a common cancer with circa 470 cases diagnosed in Ireland in 2018;
- There are circa 4,000 bladder cancer survivors living with the disease in Ireland;
- Cancer bladder is very expensive to treat but yet it is under-researched.

2

A difficult treatment for bladder cancer patients

- Patients require surgery to remove the tumour with follow up chemotherapy or immunotherapy directly into the bladder;
- The treatment course can run to 3 years with regular camera tests every 3 months for the first 2 years and then 6 monthly for the next 3 years and annually thereafter;
- This treatment journey has a negative impact on the quality of life for patients

3

Proposed solution for Dragon consideration

- To date there has been little research on the experience of patients and therefore there is limited understanding among the research community of the patient needs;
- Hence in the absence of knowing the patient need it is difficult to respond with innovation or intervention that benefit the patient;
- The proposal is that researchers **engage with patients to build an understanding of their need**. Hence a series of interviews & qualitative research is planned with bladder cancer patients.

4

Approach to the research

- Develop a questionnaire and a survey;
- Test / pilot the questionnaire with patients;
- The questions should address the type of impacts which bladder cancer patients experience, hence need to test to ensure the wording is appropriate and close the gaps;
- The current draft questionnaire is part of an international study and therefore is at a relatively mature stage in terms of draft / design;
- It is hoped that the local Irish study on needs of bladder cancer patients will be part of the larger international study.

Questions

1. **What contact strategy should be used for recruiting patients to participate in the research survey**
2. **What protocol should be used for contacting patients depending on the stage i.e. at diagnosis, pre-surgery, post-surgery, etc.**
3. **Any suggestions on how research findings can be used**
4. **Would people be willing to agree to participate in research before a formal diagnosis is confirmed**
5. **Is it appropriate to ask people their sexual orientation**



Information gathering – qualitative research with cancer bladder patients to understand their needs

Table 10

Impact of non muscle invasive bladder cancer on quality of life (2 of 2)

Insights sought from patients

1. **Best approach to recruiting patients for bladder cancer research;**

Best approach to recruitment

1. A nurse should be present at the time of diagnosis to explain the recruitment for the research to the patient
2. The nurse should be well briefed and able to explain the study context to the patients

Tips and suggestions for recruitment:

- A **standard briefing document** should be used;
- **Sufficient time** should be taken to discuss the briefing document with the patient;
- When discussing the brief with the patient it is important to emphasise it is a **voluntary choice** for the patient to decline or accept to participate in the research interview;
- Very important to commit to providing participants **regular updates**. It is important to keep the patient informed on the findings from the research;

The local Irish survey will join an International survey which is being led from Australia

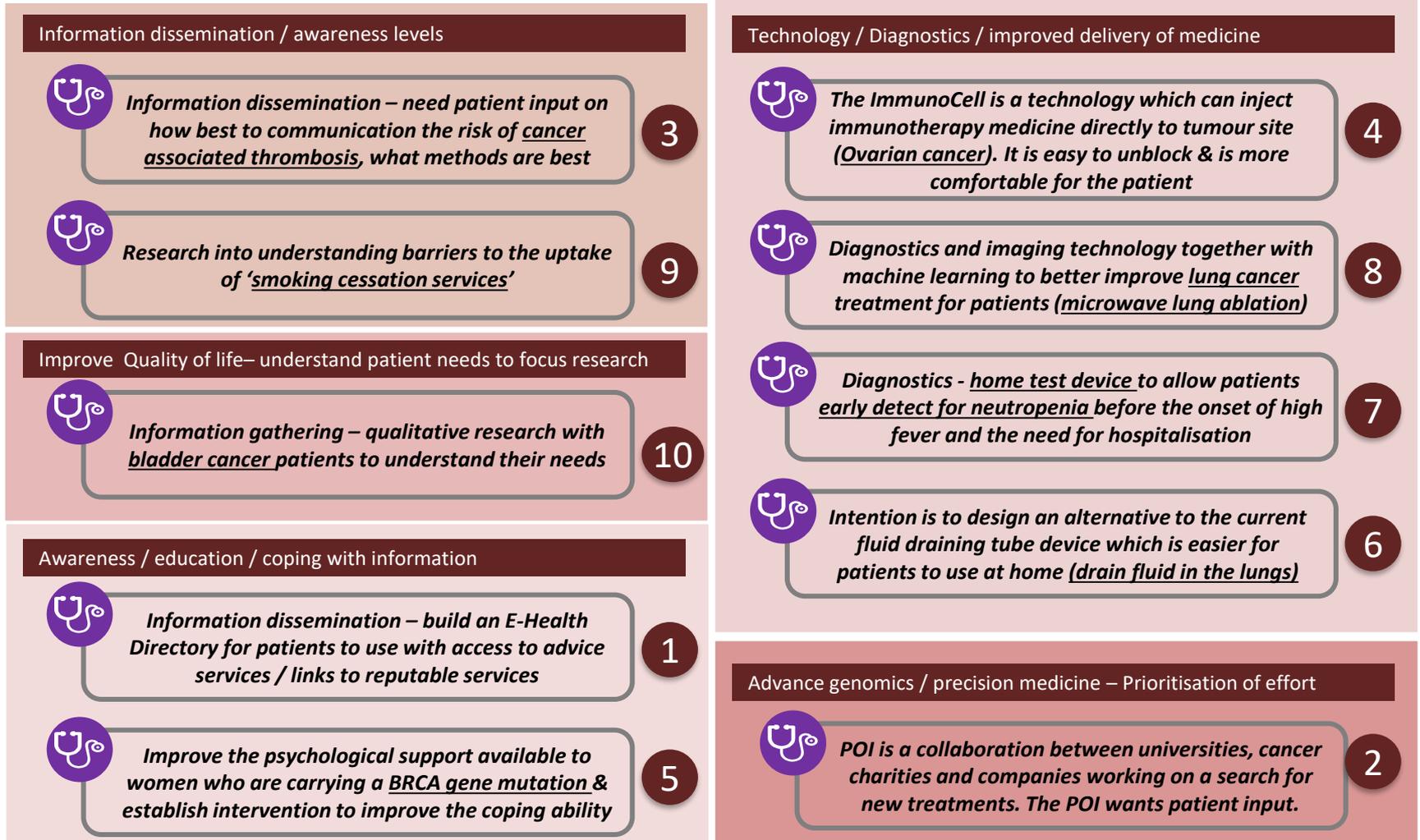
In some regards the scope to modify the survey is limited as it is feeding into an international study

Question	Patient response
Is it ok to have a question on sexual orientation	<ul style="list-style-type: none"> ▪ Patients agreed this question was ok but suitable for an online survey only and not appropriate for a paper based survey
Length of the questionnaire	<ul style="list-style-type: none"> ▪ Patients suggest it should not be too long and should require a maximum of 20 minutes to complete
Type of survey	<ul style="list-style-type: none"> ▪ Strong preference for an online survey over a paper based survey ▪ Discussion that online survey can be distributed via email or even via Whats App in the future
A question on the type of healthcare system (Public or Private)	<ul style="list-style-type: none"> ▪ The group suggested that it would be good to include a question on whether the participant is accessing treatment via 'Public Health' or 'private Health'



Information gathering – qualitative research with cancer bladder patients to understand their needs

Categorisation of initiatives



Summary findings

<p>Table 1</p> <p>E-Health Directory</p>	<p>The project is working to produce an 'E-Health Directory which serves as a credible authentic information hub'. The 'E-Health Directory' would contain validated facts & links to services. This would give patients access to reliable information sources and advice.</p>	<p>Patient voice on information needs and issues with information</p>	<p>Patients feel they are not supported and feel that advice is limited.</p> <p>Patients feel vulnerable when side-effects occur, often having no warning of what to expect.</p> <p>The diagnosis together with unexpected side effects makes for a psychologically testing time.</p> <p>A dilemma for patients is when oncologists provide advice it can be difficult for patients to process information, as such patients may be overcome by the enormity of the message.</p> <p>A reference book would be useful, patients could refer to this book or master guide as required and it could serve as an official guide.</p>
		<p>Current sense of desperation among patients</p>	<p>Patients feel alone and isolated, they can be reliant on other patients for information and insight</p> <p>The stress and psychological challenge should not be under-estimated.</p>
<p>Table 2</p> <p>POI (Precision Oncology Ireland) & patient role</p>	<p>The POI (Precision Oncology Ireland) is working to build genomic profile data to develop new therapies and diagnostics that can improve the outcome for cancer sufferers. The POI has committed funding of €11.9m for 5 years and is looking to involve patients as part of the prioritisation of the work programme. The POI has an initial patient involvement plan which needs refinement</p>	<p>Patient reaction to the draft 'Patient Involvement Plan'</p>	<p>Patients are supportive of a patient involvement plan.</p> <p>Patients want a meaningful role & want to contribute in a positive way.</p> <p>There should be patient representation on the governance board.</p> <p>Patients support the use of public meetings to build awareness & communicate key messages.</p> <p>The POI and Patients should facilitate a community type engagement, i.e. the POI should go out to the community and setup patient groups</p> <p>Important that researchers in POI have suitable training to facilitate patient groups and manage what may be emotive discussions for patients</p> <p>Out of pocket expenses should be paid and should be recognised in the budget as part of the grant application</p>
		<p>Key concern</p>	<p>Patients want more than a token role</p> <p>Training for both the researchers and the patient is important</p>

1

Information dissemination – build an E-Health Directory for patients to access information / reputable services

2

POI is a research collaboration between universities, cancer charities and companies & wants patient input

Summary findings

<p>Table 3</p> <p>Awareness on risk of thrombosis triggered by cancer</p>	<p>This projects is working to ensure all cancer patients are informed and aware of the risks of cancer associated thrombosis; The outcome of the project should be that cancer patients know the signs of a clot and know the steps to take and do apply FAST action;</p>	<p>Patient suggestions for information material</p>	<p>The information cards should have strong messages on the level of pain experienced.</p> <p>The cards should shock with facts and carry impact which result in effective message recall.</p> <p>Cards should provide tips on how to avoid thrombosis such as regular movement & hydration</p> <p>Information on thrombosis risk should be provided at the treatment planning phase & early.</p> <p>Advice to patients should be given by either the clinician or the nurse</p> <p>Patients should be given an information booklet at the time of diagnosis</p>
<p>Table 4</p> <p>ImmunoCell implanted device</p>	<p>Treatment of ovarian cancer is challenging, it is difficult to deliver effective medicine to the target tumour site post the tumour resection surgery. The innovation is a device which is implanted in the abdomen at the time of surgery and attached to a port on the skin. It can deliver immunotherapy to kill cancer stem cells at the site</p>	<p>Patient reaction to the ImmunoCell innovation</p>	<p>Patients worry about the size of the device in the abdomen and the extent of discomfort.</p> <p>If the drug delivery is effective then it outweighs any discomfort with the implantation.</p> <p>Patient interest in knowing lessons based on suitable comparisons with other medical implant devices in areas such as cardiology</p> <p>Patient interest in how the medicine attaches to the port and how it works in practice.</p> <p>Some concern regarding side effects such as bleeding or infection risk with a device implant.</p>
		<p>The problems / issues with the current treatment</p>	<p>It is difficult to get the balance between the sufficient medicine concentration while avoiding toxicity side effects;</p> <p>At present the only method for achieving a targeted delivery to the abdomen is by using a catheter which is subject to blockages and is very uncomfortable for patients;</p> <p>Patients need to be turned every 15 minutes after treatment to help disperse the medicine</p>

3

Patient input on how best to communication the risk of cancer associated thrombosis, what methods are best

4

The ImmunoCell can inject immunotherapy medicine direct to tumour site. Requires a device to be implanted

Summary findings

<p>Table 5</p> <p>Support in respect of BRCA mutation</p>	<p>In Ireland the level of support to women following a BRCA mutation diagnosis is low. This study seeks to put in place an intervention which is effective & informed by the findings of a review of previous interventions and qualitative interviews with women</p>	<p>Tips for the intervention (on-line tool)</p>	<p>Should provide tips on how to speak /Inform family members if you carry the BRCA mutation;</p> <p>The intervention tool should contain personal stories with a level of interest;</p> <p>Should contain a combination of written content and video material;</p> <p>The on-line tool should provide a simple guide on BRCA mutation and recognise that genetic testing is relatively new and still unknown, thus explaining via tips is considered appropriate.</p>
<p>Table 6</p> <p>Home draining fluid device</p>	<p>NUIG are working on designing an alternative to the current tube device for draining fluid build up in the lung. The team wish to design the alternative with patient input so that current flaws can be removed and a more user-friendly device will be available for patients</p>	<p>Functional requirements that patients find beneficial</p>	<p>Ability to self-drain daily;</p> <p>Avoid the need for a large pipe by designing a small port for under the arm which would be water-proof (allowing patient to swim or shower);</p> <p>Avoid the need for a surgical tunnelling procedure;</p> <p>A more comfortable to use design and a more discreet device;</p>
		<p>The problems / issues with the current fluid draining method</p>	<p>The patient requires support to drain the fluid;</p> <p>Installation of the tube requires an invasive tunnelling procedure which is painful;</p> <p>The external pipe & valve is large and cumbersome;</p> <p>The wound needs to be dressed constantly and kept dry which limits activities such as swimming and showering</p> <p>The patient needs to pump out drain every 2 to 3 days</p>

5

Develop an intervention for women with a BRCA mutation diagnosis via an on-line psycho-education tool

6

Seeking patient feedback on designing a home draining fluid device which is easy & comfortable for patients

Summary findings

<p>Table 7</p> <p>Neutro-check</p>	<p>This innovation is a 'Neutro-check' which is a home monitoring device so patients can self-monitor and detect 'Neutropenia' early before a high fever develops. Normally with late diagnosis, the patient is hospitalised. Early detection allows for outpatient treatment.</p>	<p>The positives / patient response to idea of a home device</p>	<p>All patients considered the Neutro-check home device to be a great innovation;</p> <p>Extending the functionality of the Neutro-check to include other sensors such as heart rate would be a good idea;</p> <p>The Neutro- Device is still in development & requires another 2 years before it is available;</p> <p>Patients value the fact that Neutro-check gives patients a level of control & peace of mind;</p>
		<p>The issues for patients which are negative in nature</p>	<p>The level of information on side-effects is poorly communicated to patients. There is no structured or consistent messaging;</p> <p>More comprehensive information on full range of side effects would give patients a better sense of control;</p>
<p>Table 8</p> <p>Microwave lung ablation</p>	<p>Microwave Lung Ablation treatment is an alternative to surgery, requires no anaesthetic only a sedative. Using a catheter & imaging technology it can position a probe at centre of tumour and use microwaves to heat / kill tumour cells with no damage to healthy tissue.</p>	<p>The positives / patient benefits</p>	<p>Avoids surgery and anaesthetics. Avoids the trauma post surgery with risk & fear of infection</p> <p>Avoids the scarring of surgery, which serves as a permanent reminder to the cancer</p> <p>Avoids a lengthy stay in intensive care which is demanding for the family and costly</p> <p>A one step / one time procedure for patients is very attractive</p>
		<p>The negatives / patient concerns</p>	<p>If 'microwave lung ablation' does not work, patients wonder what options may be available</p> <p>Also patients concerned as to how the success of the procedure is evaluated and if the tumour can reoccur</p>

7

Neutro – check is a home device monitor for early detection of Neutropenia

8

Microwave lung ablation is an alternative to surgery in lung cancer, can apply microwaves to kill tumour cells

Summary findings

<p>Table 9</p> <p>Smoking cessation in cancer patients</p>	<p>Research will be undertaken with cancer patients attending SVUH, the Mater Misericordiae University Hospital, and St. Luke’s Radiotherapy Hospital; The research will explore reasons for a low uptake of smoking cessation services among cancer patients</p>	<p>Suggestions from the dragons</p>	<p>Recruitment of participants for the research should have a balance of people who recently quit smoking, people who may have quit a long time ago and people who quit but relapsed</p> <p>In terms of people currently in treatment the suggestion is that they be given a choice if interested to take an interview during treatment or wait till after the treatment</p> <p>The interview diagnostic should explore some negative aspects such as emotional trigger of guilt & shame, the fear of not being cured or the threat of the cancer returning in the future</p> <p>The diagnostic should consider positives such as a better quality of life post quitting & willingness to try successful cessation programs e.g. NRT, acupuncture</p> <p>Probe with people the role of family and other support services in helping quit smoking</p>
		<p>Tip</p>	<p>The interviewers should have good interview technique & be able to probe in the correct way</p>
<p>Table 10</p> <p>Quality of life for non-muscle invasive bladder cancer patients</p>	<p>The proposal is that researchers engage with bladder cancer patients to build an understanding of their needs. Hence a series of interviews & qualitative research is planned with bladder cancer patients. It is intended that a local Irish study on needs of bladder cancer patients will be joined with a larger international study</p>	<p>Approach to recruiting</p>	<p>A standard briefing document should be used;</p> <p>Sufficient time should be taken to discuss the briefing document with the patient;</p> <p>When discussing the brief with the patient it is important to emphasise it is a voluntary choice for the patient to decline or accept to participate in the research interview;</p> <p>Very important to commit to providing participants regular updates. It is important to keep the patient informed on the findings from the research</p>
		<p>Other preference</p>	<p>Prefer an online survey to a paper based survey</p> <p>The survey should not be too long and should not take more than 20 minutes to complete</p> <p>Survey should ask if the patients access to health care was via “public” or “private”</p> <p>It is ok to include a question on sexual orientation once the survey is an online survey</p>

9

Research into understanding barriers to the uptake the ‘smoking cessation services’

10

Information gathering – qualitative research with cancer bladder patients to understand their needs