Patient Panel

It Matters to Me

NHS
The Princess Alexandra
Hospital
NHS Trust

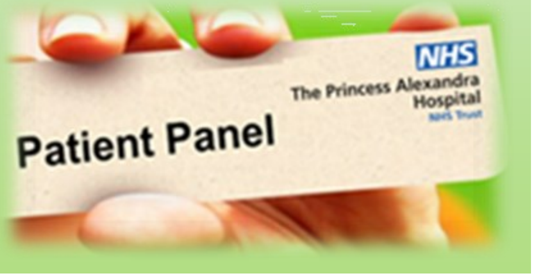
26th March 2018

NHS
West Essex
Clinical Commissioning Group

Authored by:
Ann Nutt, Shahid Sardar, Tina Smith

Help us shape your local cancer services

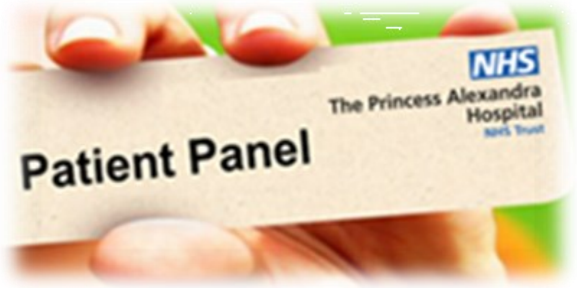
WE ARE
MACMILLAN.
CANCER SUPPORT



It Matters to Me
Content

Contents	Page(s)
Introduction from the patient panel	Page 1
How do Cancer Services work?	Page 2-3
An evidence based approach including the GP survey	Page 4-8
A patient experience link to videos with thanks	Page 9
Workshop evaluation findings and recommendations	Page 10-14
Conclusions	Page 15-16
Macmillan Survey	Pages 17-24
Cartoon Illustrations	Pages 25-28
Appendix 1: Directory of local Cancer Services	Pages 29-39

Introduction



Ann Nutt

Chair of the Patient Panel

This report is the result of a conference that was run in partnership with The Princess Alexandra Hospital NHS Trust, the Patient Panel, West Essex CCG (Clinical Commissioning Group), MacMillan Cancer Relief and the Sustainability and Transformation Partnership (STP) for Hertfordshire and West Essex.

This is the fifth conference conducted by the Patient Panel, each of which has been on a specific topic of current interest. Cancer care was chosen following the excellent results that PAH obtained in the National Cancer Patient Experience Survey, however improvements can always be made and with the teams that support cancer care at PAH and the STP (Sustainability and Transformation Partnership) and the teams working on different elements of the pathway, the Patient Panel decided with the support of these teams to hold the conference to find out what really matters to patients on this journey.

The conference was entitled What Matters to Me and the emphasis was placed on how local people can shape local cancer service, what we need to improve and what we already do well.

Before the conference took place a face to face questionnaire was completed with the aid of students from Harlow College at a local GP (General Practitioners, these are doctors who work in your local community at a Surgery) training event. GPs were kind enough to give honest and open answers to the questions raised in the questionnaire with regard to the fast track referral system and relationships with senior clinicians. The result of this survey are given at the end of this report.

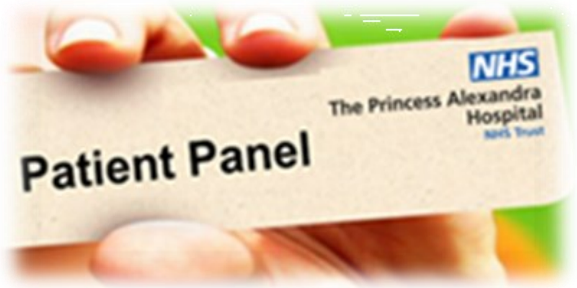
This piece of work demonstrates better practice when working in co-production with patients at the heart of the work. The work was patient led, with the patient panel being the lead organising, creative and delivery mechanism.

The Patient Panel

If you'd like to join us in helping change your health and social care services in your area, then the Patient Panel would welcome your contact and support in making things better for everyone.

Email us at patient.panel@pah.nhs.uk

How do cancer services *work*?



The PAH provides a comprehensive range of acute and specialist oncology (cancer) and haematology (blood analysis and testing) services for Harlow and the surrounding communities from Buckhurst Hill in the south to Saffron Walden in the North to a local population of about 350,000 people.

Last year the service received over 15,000 urgent suspected cancer referrals. The team is made up of over 64 people from various disciplines and they support 12 different tumour sites (like lung, prostate, breast, bowel, pancreas).

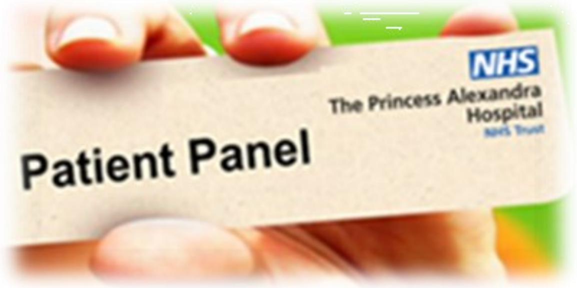
The service is delivered largely through a day unit based in Harlow, the Williams Day Unit and is part of the London Cancer Network with close links maintained with Tertiary referral centres (like University College Hospital in London).

The hospital has been rated highly for the delivery of cancer service for a number of years as a result of pioneering work done by the Epping Breast Unit, but also performance against the national cancer standard.

Why this conference?

The conference came about as a result of the National Cancer Patient Experience Survey and the nature of Cancer Services which operate across boundaries. We know that there is learning to be gained from working with our partners across the regions of Hertfordshire and West Essex as each of these teams has their own strengths and weaknesses. The STP (Sustainability and Transformation Partnership) has brought these different organisations together to take a strategic perspective on how services develop across the region and patient centred approach was needed.

How do cancer services *work*?



A Co-production Approach

As a result of this the Patient Panel at PAH got involved and ultimately led the development and delivery of this event and will be involved in delivering the outcomes.

Some of the objectives which were described at the outset and agreed with the STP (Sustainability and Transformation Partnership) and CCG (Clinical Commissioning Group) who co-funded the event were as follows:

Objectives

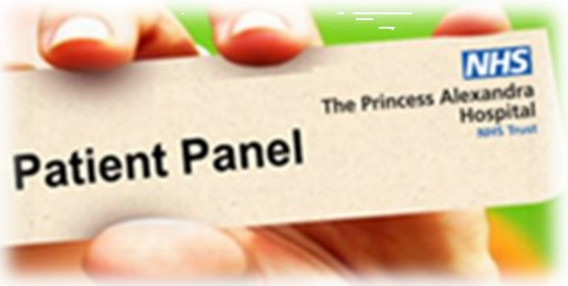
- To develop a Princess Alexandra Hospital Trust Cancer Patient Family and Carer Experience Group.
- To ensure that any event or user group established following the Cancer Patient Experience Conference would to recruit a wide range of representatives of the local community including underrepresented groups to identify unmet needs.

Results

- Worked in partnership with the Patient Panel and Patient Experience team to identify patients who would be interested in joining the Cancer Patient Experience Group.
- The first meeting is being planned for June 2018.
- TOR (terms of reference) to be drafted and agreed following the first meeting.
- Been in touch with a range of local minority groups such as the Chinese Community, the Islamic Centre, the Harlow Ethnic Minority Umbrella, Young Concern and Essex County Council Youth Services and the Prince’s Trust.

Based on this evidence, work which needs to be done to respond to the requests and expectations of the public who attended the Conference is well underway.

An evidence based approach



How we put together the conference

Both sets of findings are reported below and provide the rationale for the conference structure and planning (workshops, videos, audience, speakers and facilitators). So for example:

- A workshop on holistic needs as GPs were often left bearing the brunt of post diagnostic support, despite the number of charities set up specifically to help families impacted by cancer
- A workshop on medication and side effects took place as a result of the low scores observed in question 15
- MacMillan voluntary sector teams participated based on the finding of poor support post discharge (not necessarily all medical, but also social needs) as well as a workshop on the role of carers
- Paediatric oncology staff were made available to facilitate a workshop based on anecdotal evidence of weak transitional care
- The lived-experience of patients needed to be visible on the day, but the organisers did not want to put patients in the emotionally challenging position of speaking to a large audience, and so two videos were commissioned, which will be used for information and training by the Cancer MDT (multi-disciplinary team).

National Cancer Patient Experience Survey Results (NCPES)

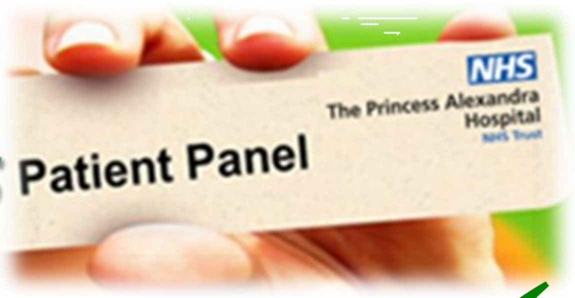
Conference drew on the evidence of the National Cancer Patient Experience Survey and informed by a local GP Survey conducted exclusively for the Conference.

This section lists the findings of the NCPES last year.

Key messages

- Saw GP once/twice before being told had to go to hospital **80%**
- Thought they were seen as soon as necessary (Primary Care) **85%**
- Length of time waiting for test to be done was about right **90%**
- Given complete explanation of test results in understandable way **82%**
- Patient given understandable information about whether chemotherapy was working
- **70%**

Positive Improvements



Positive Improvements

Results of tests explained in a way that was understood

75% → 82%

Involved as much as you wanted to be in decisions about care and treatment

70% → 79%

Member of staff explained after operation how it had gone in a way you understood

69% → 79%

Family, or someone else close were able to talk to doctor if they wanted to

61% → 67%

During cancer treatment, given enough care & support from health or social services

33% → 49%

Questions scored outside the expected range

Q15 Definitely told about side effects that could affect them in the future **48%** (national av. 54%)

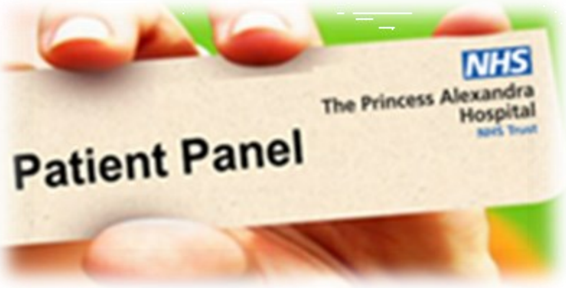
Q28 Group of doctors or nurses did not talk in front of patient as if they were not there **71%** (national av. 82%)

Q32 Always/ nearly always enough nurses on duty **57%** (national av. 67%)

Q39 Staff told patient who to contact if worried post discharge **89%** (national av. 94%)

Q44 Beforehand patient had all information needed about radiotherapy treatment **72%** (national av. 86%)

GP Survey

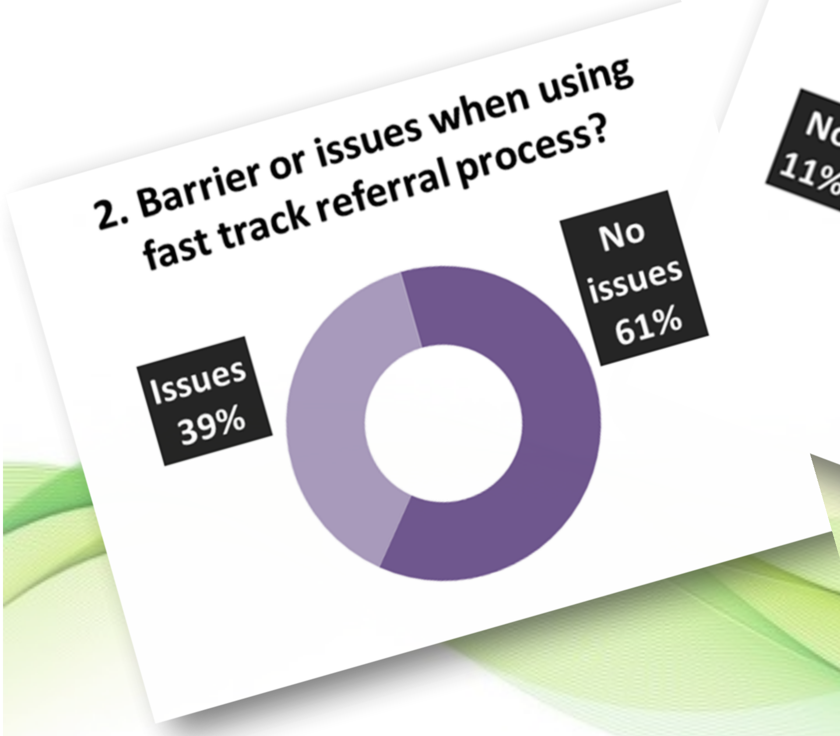


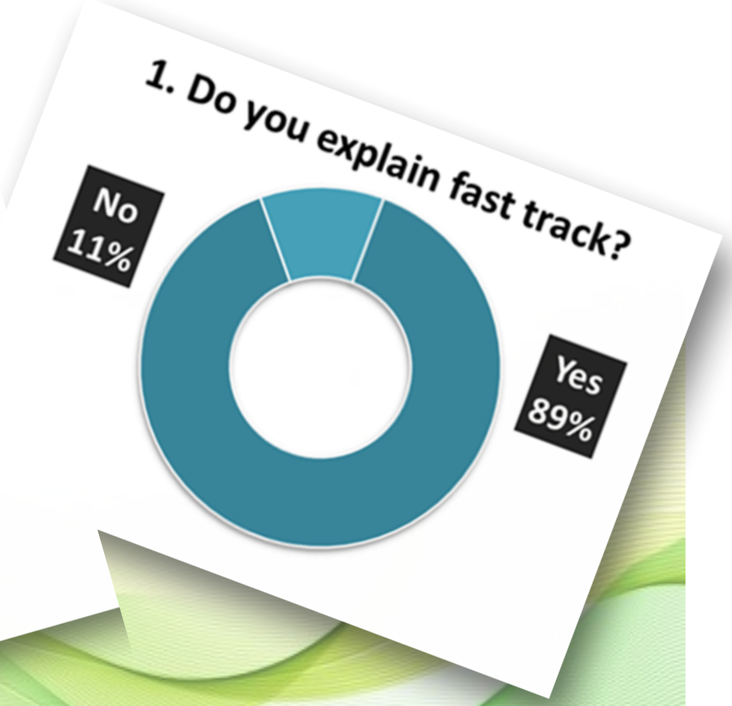
The Survey was carried out at a West Essex CCG (Clinical Commissioning Group) training day for GPs (General Practitioners) on 22 March 2018 in partnership with a cohort of current health and social care students from Harlow College as part of a live brief, supported by the Patient Panel.

The CCG event coordinators worked with the Patient Panel to ensure we captured as many GPs views as possible. We did this by interviewing for the Survey between 12.30 and 1.15 to cause the least disruption possible to the training and audit day. Approximately 100 GPs attended and we obtained 36 completed forms.

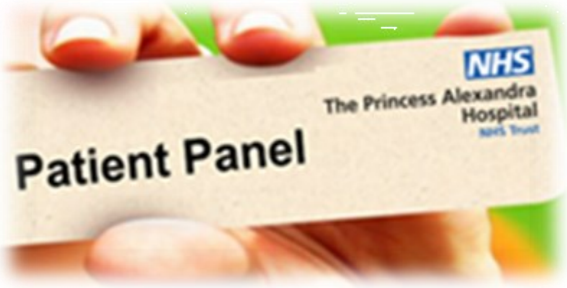
Not all those attending were GPs, we also spoke to specialist nurses (both community and hospital) and practice managers, and took their verbal responses if they felt confident enough to answer the questionnaire.

The results of the survey are as follows with some of the comments compounded into one 'generic'





Comments



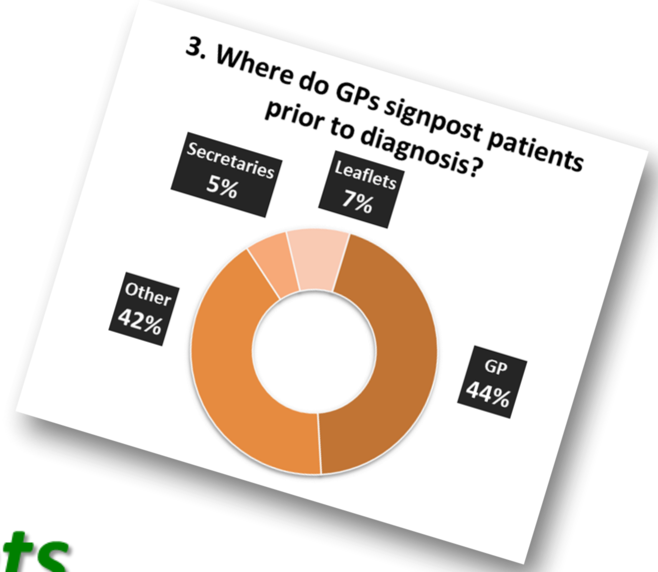
- Two GPs admitted: ***"It's very difficult to tell the patient they may have cancer"*** and one said they would ***"not want to make the patient anxious"***

- Three GPs said ***"too much paperwork"*** and one said ***"filling in the criteria/ forms difficult to complete on-line".***

- One GP commented that ***"patients don't rebook when they are unable to attend an appointment"*** and others said holidays and relatives also play a key role.

- Fast Track works, but there are problems later with system overload

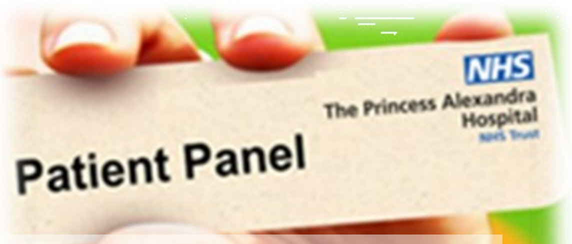
- Treatment is not always local to patient



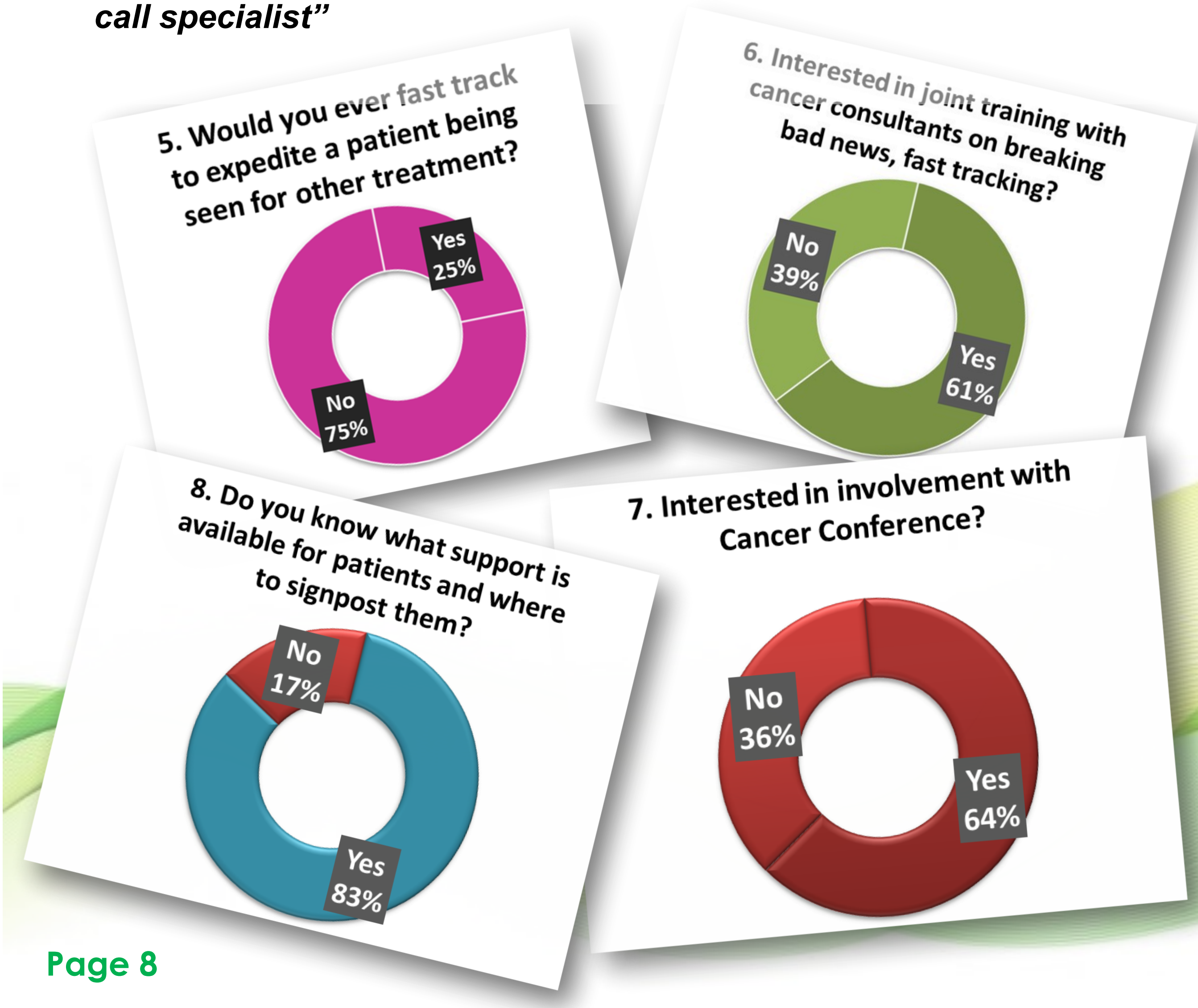
Further Comments (42%)

- Refer to Care Navigator (this is available in the voluntary sector)
- Discuss the uncertainty – likely not to be cancer
- Note: GPs states that leaflets produced by CCG (Clinical Commissioning Group) are not accessible on-line as for some the IT is not compatible
- Online cancer resources
- Cancer Information (MacMillan)
- Support from Specialist Nurse
- St Clare's Hospice (a local hospice)

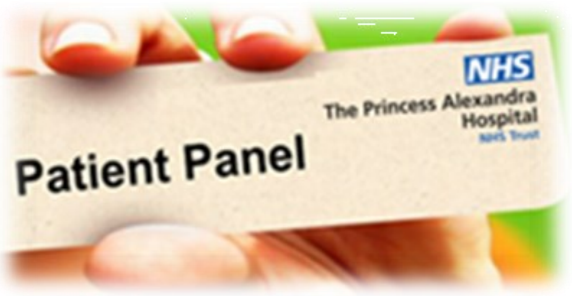
Support required in the *process*



- Seven GPs stated they needed more tailored written information
- Three stated that earlier or specialist nurses would help and how to contact them
- Several admitted to needing to learn more, about ***"how to deal with patients", "knowledge about the process" "social support"*** and one mentioned ***"emotional concerns",*** lastly one stated any support would help.
- One stated a need for a safety net until a patient gets an appointment
- One GP asked that more routine screening takes place and another that more time is offered for appointments
- One GP said ***"Not at the moment, if I've any problems, I contact on-call specialist"***



Patient Experience *Video's*



The Patient Panel would like to thank the two patients who consented to participate in filming and thereby enabled the conference participants to discuss difficult subject matter.

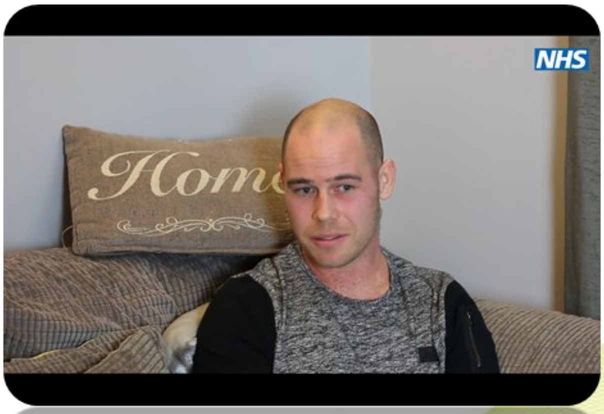
These videos portray two courageous people who offer an insight into their cancer journeys and enabled people in the workshops to be equally open and honest. We say courageous, because Pat and Ben have expressed very personal and difficult issues in a very human way, something which we can never completely express our gratitude for.

The videos also offered an insight for professionals who might otherwise struggle to understand what the human experience of cancer feels like, warts and all. Both links are attached below and can be accessed by clicking on the electronic form of the report or by typing in the link

https://youtu.be/7t0PRBgPV5I

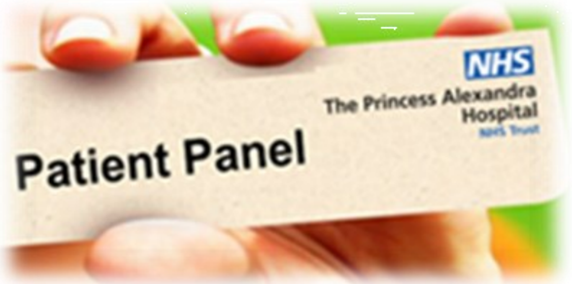
This link is for Pat Walsh,
she is ill with cancer.

https://youtu.be/Fv9o2adTh8s



This is Ben Thurley,
a younger person with a young family.

Workshop Findings
Money Matters



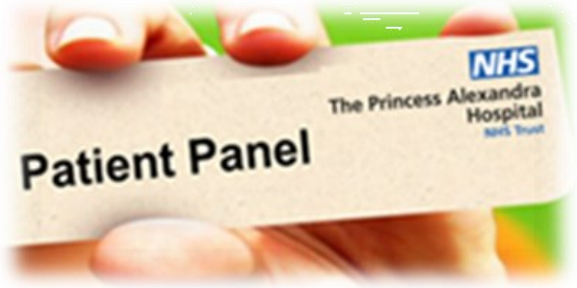
Issues Highlighted

- Hospital parking should be made easier for patients receiving cancer treatment
- How are patients made aware of benefits available
- How do you support patients with a dual diagnosis or needs
- People are often uncomfortable speaking about money, due to issues of personal pride and dignity
- A directory of services needs to be made available so that patients are not spending money unnecessarily (see Appendix 1)
- What support is provided where patient is self employed, as this has a significant impact on the kinds of issues
- Heating costs and bills can be subsidized but often people don’t know until much later in treatment process

Recommendations

- This item has been taken up by the Patient Panel who will work with the hospital on designing the concession policy and implementation for car parking
- Collaborative working to continue with Macmillan Cancer Support in the development of a Drop in Benefit Service in Williams Day Unit, with the new service being in place by December 2018
- Holistic Needs Analysis information will need to be enhanced to include the needs of patients with multiple needs including non-medical effects of cancer.
- Improve access to patient information at key stages of the patient pathway with greater emphasis to be placed on identifying patients’ and careers' needs in relation to financial support and advice not only at diagnosis but following treatment
- The Williams Day Unit refurbishment this year must ensure improved facilities for the Macmillan Information Hub and the outpatients clinic area with dedicated room for patients to be seen in private to discuss their financial concerns
- Staff to be released for training to update their knowledge regarding benefits and financial services
- Information about the Information Support Service needs to be more widely known and explained, consideration will be given to developing a patient folder with relevant information and contact numbers.

Who Cares?



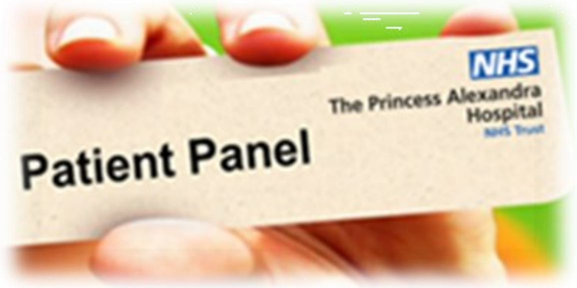
Issues Highlighted

- Who cares for the carers, what support is available
- Often there are delays getting support and there is anecdotal evidence that some professionals don't communicate well with carers
- A number of carers emphasized that they did not receive information at the right time, information should be preventative, rather than simply getting support in a crisis.
- How do I get respite care when needed

Recommendations

- Carer needs to be given proactive advice at the point of diagnosis, this should be focused information in the same way as the patient is given, on voluntary organisations that can support families, the DWP and local authorities
- Information on carers benefits

Management of Side Effects



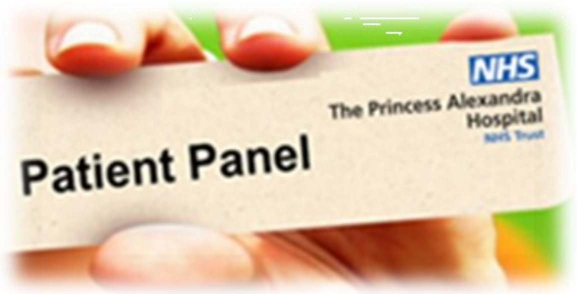
Issues Highlighted

- Honesty about possible side effects, many people would be worried about losing their hair
- How do I get additional information about my medications
- Visual Guides relating to potential side effects i.e.; use of a body map
- Treatment summaries would help at the end of treatment
- Too much information given at diagnosis

Recommendations

- Medications Helpline information needs to be given greater prominence – to be included in patient information folder
- Audit how the new Consent Form being used on Williams Day Unit has improved the information provided to patients prior to treatment, supported by the Panel who can survey on how it helps
- Continue with ongoing review of the timeliness and appropriateness of information given; the Head & Neck and Prostate Cancer CNS (Clinical Nurse Specialist) are working with UCLH (University College London Hospital) Cancer Collaborative mapping information pathways
- Greater promotion of the Cancer Hair Care Service delivered on Williams Day Unit
- End of Treatment Nurse Led Clinics to be developed, these will encompass Holistic Needs Assessment and End of Treatment Summary which will support the identification of unmet needs and support & advice in managing potential long term side effects
- Advertise Fabulous and Beautiful for women with cancer with information in folder
- Body maps to be used/offered in the oncology clinic for potential side effects
- Continue with the delivery of Treatment Summaries in the pilot sites of colorectal, prostate and breast and then roll out to all tumor sites as planned.

Life after the *challenge*



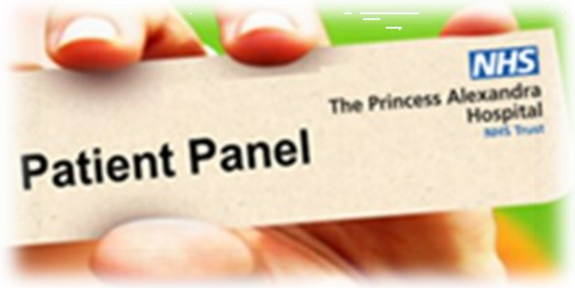
Issues Highlighted

- Macmillan Cancer Information Hub not always accessible
- Psychological support needed after treatment
- Lack of awareness of what is available
- Minimal follow up and not aware of resources available
- Empowerment

Recommendations

- Macmillan Cancer Information Hub to ensure that open times are clearly displayed
- Macmillan Partnership Application to be made this year for Level 3 and Level 4 Psychological support; work collaboratively with the West Essex CCG (Clinical Commissioning Group) with the application
- Health & Wellbeing Events to be promoted at the end of treatment reviews and within primary care
- Macmillan Recovery Package Manager to ensure that there is equitable access to the Health & Wellbeing Events
- Honest evaluation of Health & Wellbeing Events to ensure they meet the needs of the users
- Continue with the introduction of Stratified Pathways of Care within the pilot sites of Prostate, Colorectal and Breast Cancer then roll out to other tumor sites ensuring patients are safely followed up in a timely and holistic manner

Young People with cancer



Issues Highlighted

- Educate teachers (schools, colleges and universities), youth workers and their peers
- Educating GP's and hospital staff on dealing with younger patients
- Information in a format they use. Internet, Social Media, Apps in a language they use.
- Never assume anything about young people, stronger than you think
- Needs to know openly what is going on
- Help to understand it and normalise it
- Have fear of the unknown
- Volunteer Counsellors
- Extended families – different demands

Young people

"I do everything – pay bills, cook, clean, put him to bed, help him get around and give him morphine for the pain.

I comfort him and help him back to sleep."

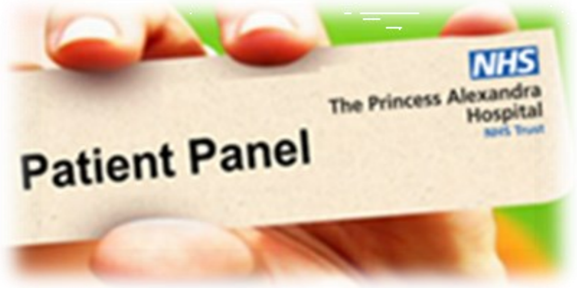
Under Pressure, the Growing Strain on Cancer Carers
macmillan.org.uk/get-involved/campaigns/carers
Accessed March 2018

Recommendations

- Aims and Objectives will be decided at the first meeting
- Name will be agreed by the young people
- Ultimately the group will be run by young people
- Literature designed and written by young people
- Training designed and written by young people
- Establish a task group including:
- Two Paediatric nurses, Patient Panel, Essex Youth Services, Harlow College, a young person with cancer, younger carer, Harlow Council, Harlow Education Consortium, Young Concern Trust, representatives from Hertford with ultimately two support networks, one for each county.

Conclusions

Key points and reflections



In conclusion it's clear to the Panel that there is lots of information out there for people impacted by cancer, people just don't know about it.

It was a real issue for **men that they do not receive the same quality of service** that women do, such as regular screening and engagement from the NHS and the media in men's health issues, this came across particularly strongly from the Prostate Cancer Support Group who were present.

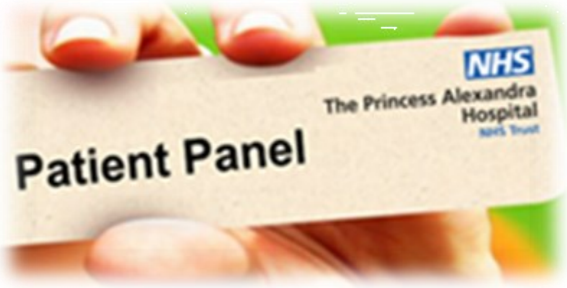
Young people were another group who had a clear message about how they wanted to be treated, parents tended to water things down for them, when they **would prefer to be told the truth in a mature way.**

Many people, were also not aware of the financial support that MacMillan offer, short term support when someone has difficulties with their work, the benefit of this was highlighted in the short film made with Ben Thurley.

The social side of a long term illness was also apparent, as a neglected subject, but that support was available, patients talked "wanted to turn around the mirror" and this is an issue which would benefit from greater focus and investment. Our ideal scenario would be that this kind of conference would become a biannual event, perhaps by using funds for Health and Wellbeing events. We say this because, patients, families and carers gained significant benefit and reassurance from ad hoc conversations with professionals, talking about the subjects which might not otherwise come up in consultations, as the event created the right kind of more relaxed environment.

Conclusions

Key points and reflections

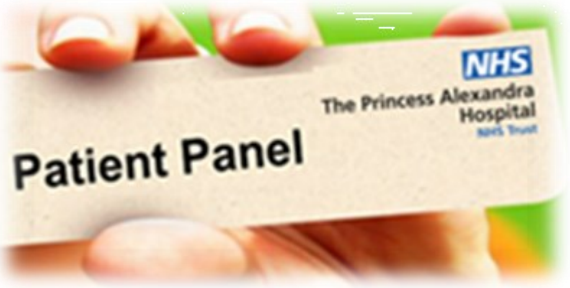


Participants evaluation

The events organisation was rated highly, the venue was completely accessible by public transport and the fact we paid for parking was appreciated, food and refreshments met all dietary needs including gluten free and lactose intolerant diets. The content of the workshops was remarked to have been 'spot on' and well managed despite the difficult subject matter. It did highlight that our evaluation scoring was confusing and so we will be redesigning our evaluation forms.

We would like to thank retired consultant Dr Gordon Read, BSc, MBCHB, DMRT, FRCR for hosting with such humour and sensitivity.

MacMillan Survey



Overview of the STP engagement event

Macmillan worked with the Hertfordshire and West Essex STP to support the planning and delivery of an engagement event, to enable PABC to share their experiences and inform local services. A focus on patient engagement, partnership working and co-production was embedded into the process or organising this event and points raised from the National Cancer Patient Experience Survey was a key driver to give deeper insights into local needs. Alongside the event, a survey was distributed to GPs by West Essex CCG This survey was coproduced with health and social care students at Harlow College and the patient panel. For more details of the event and survey, including recommendations that arose, please see the report entitled; 'Patient Panel, What Matters to Me'.

Information, support and engagement

To give a richer picture of the experiences and needs of PABC and promote our services, both the MISS and Engagement Lead attended and contributed during the event. Information and support was available and people were also encouraged to participate in an additional survey to capture experiences in the community, to ensure there was a broader picture of cancer services and potential gaps. A link to an online survey, together with hard copies was distributed. This was also circulated to local support groups to try and capture more views from isolated groups.

Survey: Evidence based approach

The survey questions were co-produced with a volunteer and person affected by cancer. The questions were also shared with a focus group for feedback, which in turn has resulted in some adjustments. The key theme raised within the coproduction phase included:

- Easy to complete survey is paramount and the option to do online and via a hard copy
- Open questions to enable people to expand on views and not be limited with answers
- Guidance to give some ideas to help alleviate misunderstanding of jargon
- Questions to capture support received outside of the Trust and treatment plans
- To invite both positive and negative experiences
- No more than 10 questions

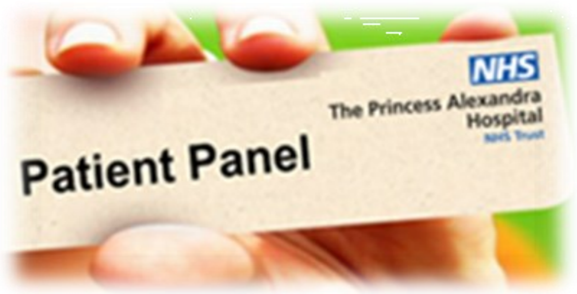
During interviews with PABC carried out by the Engagement Lead as part of the Theory of Change work, there was also a theme, recommending surveys as one way to capture evidence of need and that questions should be open around the person's experience and not just a tick box exercise focussing on feedback in trusts.

Questions asked in the survey

1. Your cancer experience. Please choose which one applies to you.

- I am or was a carer of someone who has or has had cancer
- I have cancer and am currently undergoing treatment
- I have had cancer and am now in recovery
- I am a health or social care professional supporting people with cancer

MacMillan Survey



2. Please give a brief overview of the type of cancer you or a loved one had, the year you/they were diagnosed and brief description of treatment.

If a professional, what is your role and what type of cancer/s do you support people with? (open ended comment box)

3. Have you received any support from social care services and if so, can you give a description of this support and how it affected you (positively or negatively)?

If a professional, do you work with social care services and if so how does this benefit your patients/carers and what difficulties are you faced with?

Guidance: Social care services may include things such as: Equipment, care needs assessments, care in the home, community support and activities, day centres, home adaptions, residential care, financial support, meals delivered (open ended comment box)

4**. Have you had any support from voluntary services or groups or charities? If so, can you give a description of what this was and how it affected you (positively or negatively).**

If a professional, what voluntary services or charities do you refer, signpost or work with and what is the positive impact of this/challenges?

Guidance: The type of support you received may include: counselling or emotional support, befriending schemes, neighbour schemes, telephone support, support groups, benefit or financial advice, information and support, advocacy, help at home, transport, hospice services, clubs and activities, gardening........ and so on... (open ended comment box)

5. **What other services have helped you, in the community, in relation to your cancer journey.**

If a professional, what other services have you worked with in the community that have supported your role and your patient's cancer journey?

Guidance: This service may have helped with your physical, emotional, social, financial or information needs and could include people such as: counselling through your GP or the health and wellbeing team, district nurses, health visitors, GP home visits, day care services, libraries, meals delivered, dietician, occupational therapist, physiotherapist, diabetes support at home, etc. (open ended comment box)

6. What do you think needs improving the most, in terms of cancer support in the community and why? (open ended comment box)

7. What is the first four digits of your postcode? If a professional, what is the first digits of your main place of work? (open ended comment box)

8. If you would like to know more about how you can get involved to improve cancer support services, please add your contact details here and Macmillan will get in touch. If you do not want to be contacted, please mark with an X

9. Please tick the age group relevant to you

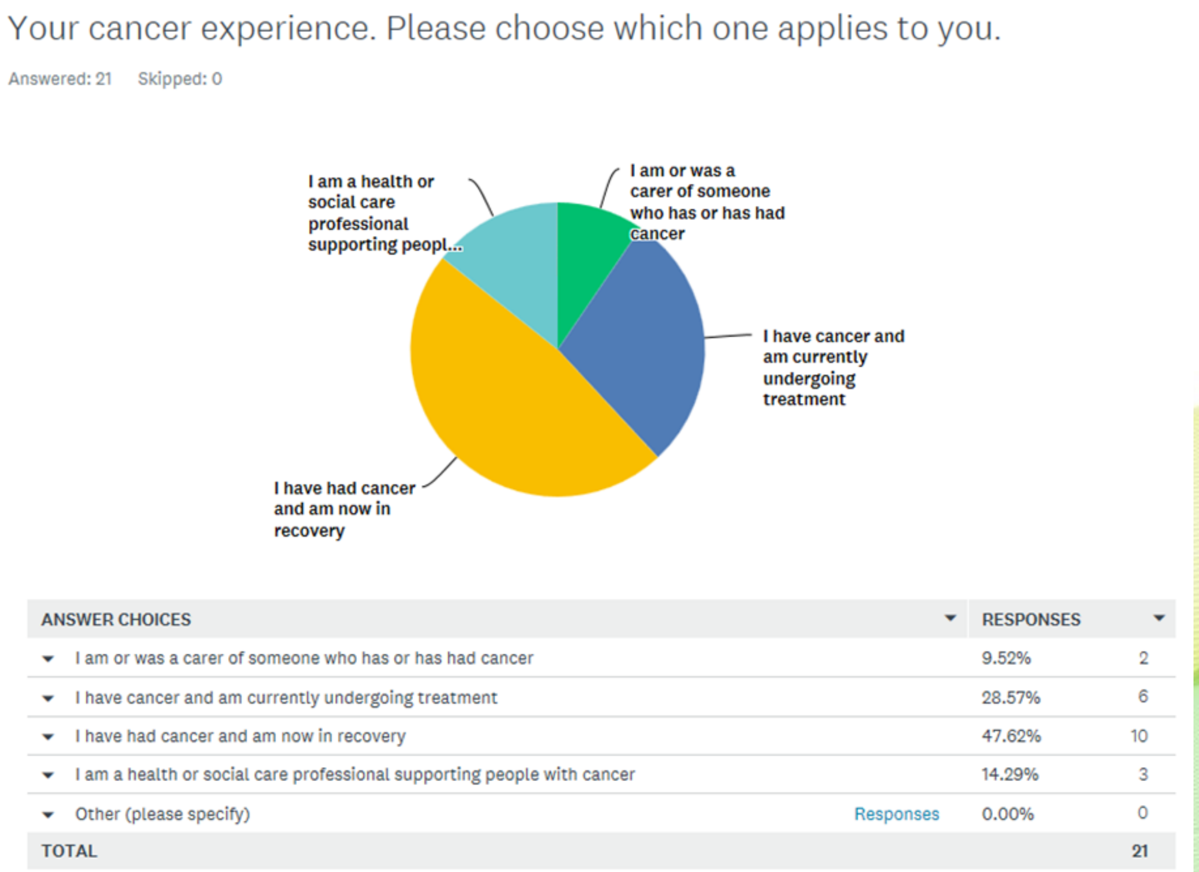
18-29 years old 30-39 years old 40-49 years old
50-59 years old 60-69 years old 70-79 years old 80+

10. If you identify with any of the following groups, please check the boxes that apply. This information helps us see who we are reaching and whether we are reaching groups that may be under represented within cancer support services.

Male
Transgender
Learning disability
Female
Black, Asian, minority ethnic
Sight impairment
Non- binary
English not as first language
LGBT community

Responses

Question 1: Who took part?



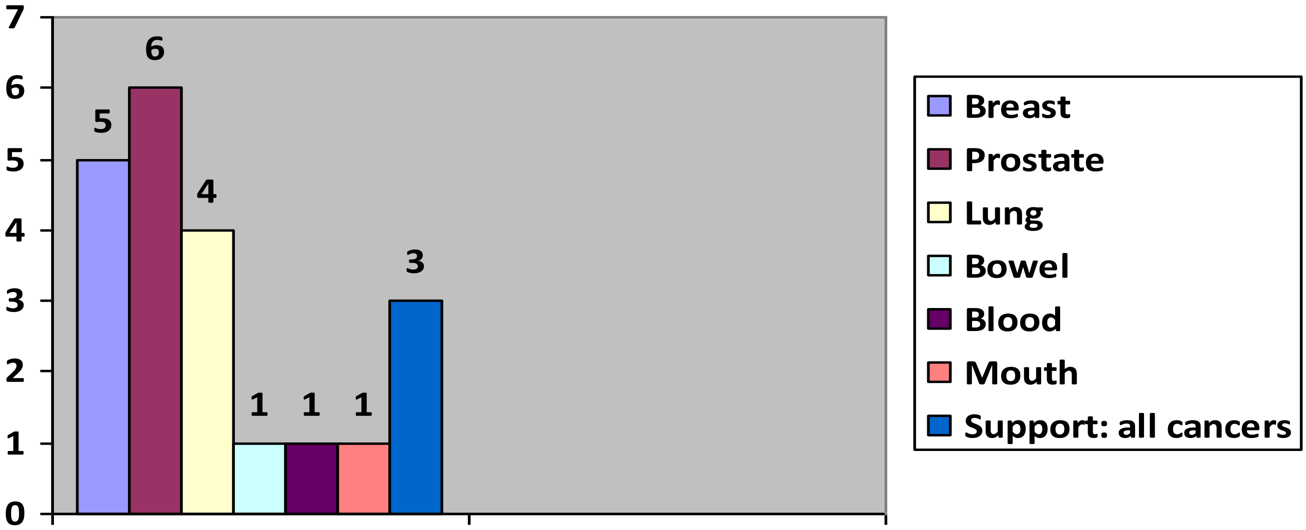
Your cancer experience. Please choose which one applies to you.

Answered: 21 Skipped: 0

ANSWER CHOICES		RESPONSES	
I am or was a carer of someone who has or has had cancer		9.52%	2
I have cancer and am currently undergoing treatment		28.57%	6
I have had cancer and am now in recovery		47.62%	10
I am a health or social care professional supporting people with cancer		14.29%	3
Other (please specify)	Responses	0.00%	0
TOTAL			21

MacMillan Survey

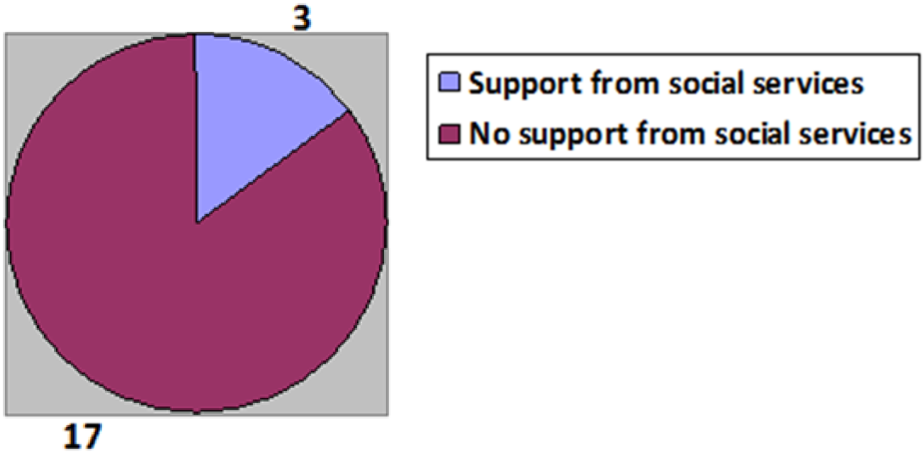
Question 2: Cancer Types



Key issues identified

- More engagement needed to get the views of PABC from a wider range of tumour sites

Question 3: Support from social care and key themes that arose



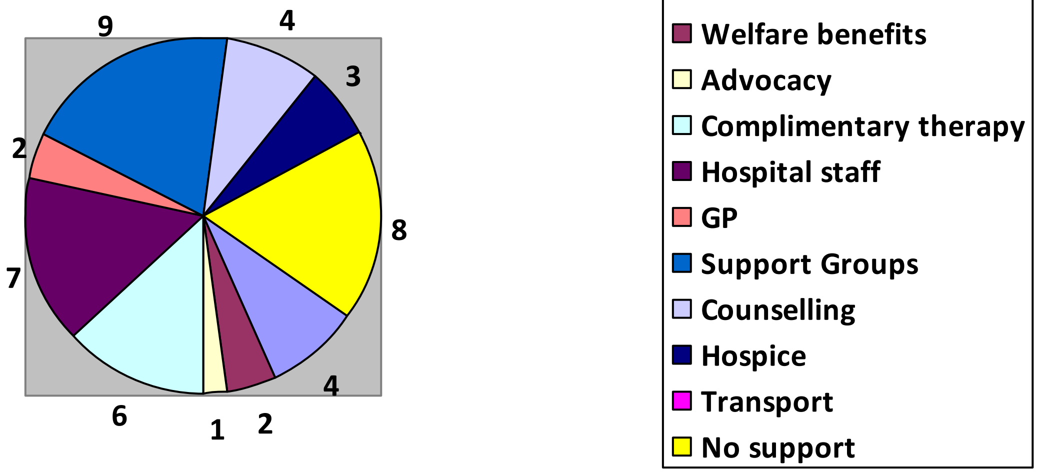
Key issues identified:

From all 21 responses, a staggering 17 said 'no' or 'nothing'; 1 said 'not needed'; 1 said they had limited help but had to self fund and the additional 2 responses did work with or refer to social services, both being health or social care professionals. Results suggest there may be a lack of 'social care assessment or signposting' input and therefore PABC may not be having access to support in the home and community. Some additional comments included:

- "I have no idea what support is available from social care"
- "I was never seen by a social worker or community team. I wouldn't know what they can offer or how to request help either at the time or in the future"
- "I had no support at all but could have done with it as was just left after any treatment"
- "I bought my own aids at home, such as a toilet raiser, as I was told there could be a long wait if referred and wanted to go home asap after surgery

MacMillan Survey

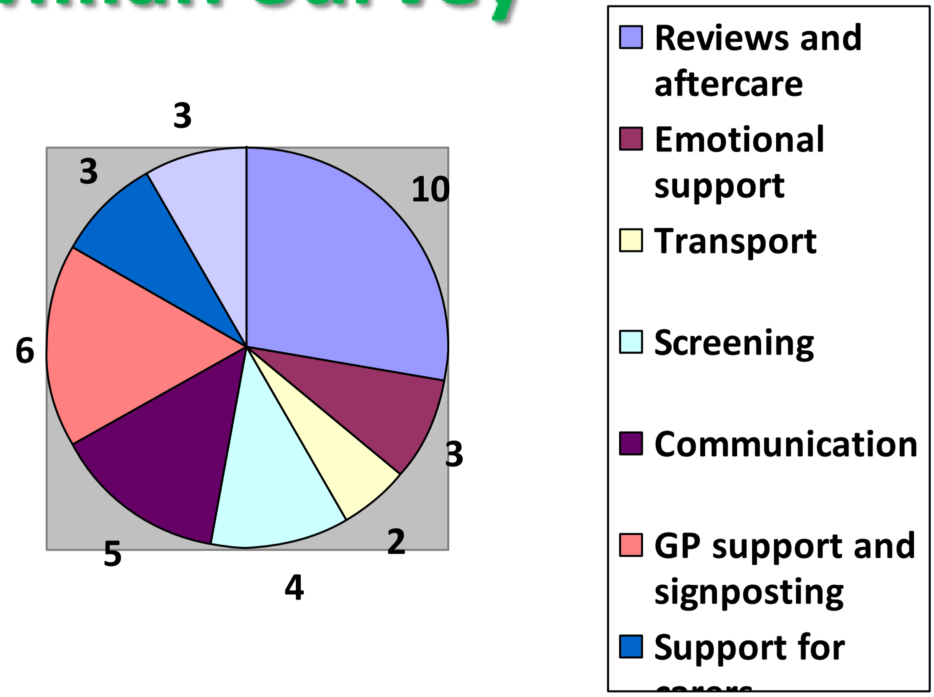
Question 4/5. Support from voluntary groups, charities and other services in the community



Key issues or themes identified:

- The two responses regarding gaining support through the GP was specific to accessing counselling. One response also included that the GP did support with regular screening but this has now stopped and no aftercare given.
- Emotional support was identified as highly important and accessed through the hospice, support groups and a complimentary therapy group. One health and social care professional stated, 'emotional support for carers is also very much needed'. Generally, the responses identified a need to signpost to this support and the need to have emotional support available across the geography.
- The support given by hospital staff (7) was specific to nurses in all responses. Examples of responses include "the CNS was amazing" "All the nurses helped me so much but were so busy" "My nurse gave me her time to understand what was happening to me".
- The advice received by PABC on welfare benefits was given by the Macmillan support line and not face to face support.
- The responses referring to Macmillan specifically, was for the website, support line and online community to access information and advice and not to any information centres or face to face support.
- No one identified having support with transport, holistic assessments or reviews, nor aftercare.
- A professional stated that she "wasn't aware of any health and wellbeing teams and community teams are very much needed locally".
- A total of 8 PABC felt there was no support available to them in the community whatsoever.

MacMillan Survey



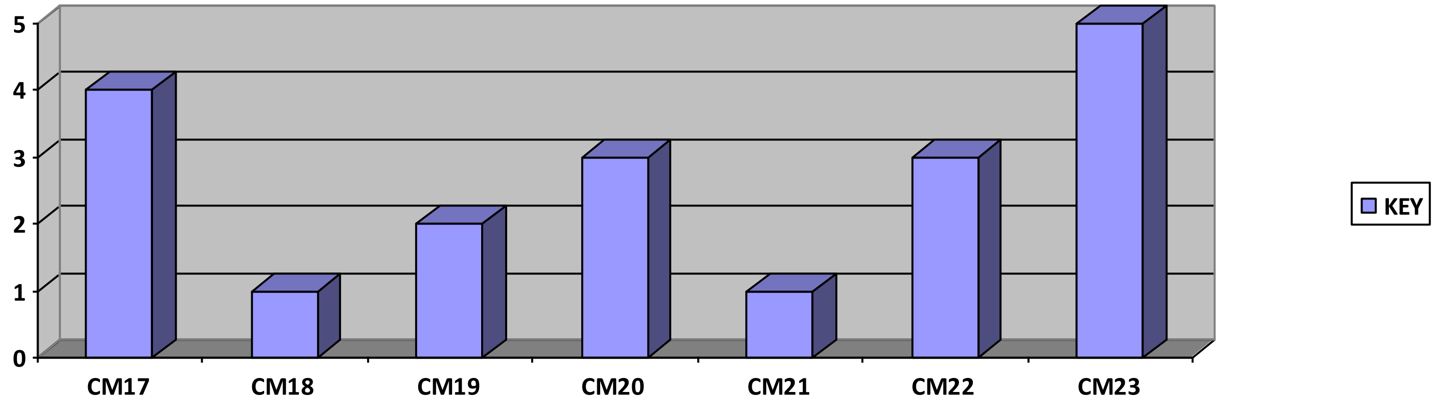
Responses include:

- “Someone to contact you at home to see how you are and see what support you need, everything is just about my treatment” *PABC.*
- “More information and some understanding and support from GP's surgery. Going to GP for advice after treatment was a nightmare, they do not read notes before the appointment so having to tell them the what and whys every time is not good.” *PABC*
- “Giving me simple information on what types of support or benefits I can get. Didn't know about additional benefits and also felt left between hospital visits and felt overwhelmed” *PABC.*
- “Early diagnosis. GP support after treatment and more information on Macmillan from GP” *PABC.*
- “More help for carers and informing me and carer of the type of support that is available as I had to find this myself” *PABC.*
- “I felt very embarrassed and couldn't talk about how I felt. No one asked me if I was coping or needed help apart from symptoms directly related to the cancer” *PABC*.
- “GP or someone to follow you up during and after treatment. Everything is just about what happens next with treatment and I didn’t understand it half the time” *PABC.*
- “There doesn’t seem to be any support outside of the hospitals. Everything is clinical. More support needed and a human conversation on how you are coping and what help is available” *PABC.*
- “Someone to contact you after you’ve been told you have cancer to see if you have any questions” *PABC*.
- “I think that GPs need to become a bit more informed about prostate cancer” *PABC.*
- “Follow up consultations and appointments on time and more regular” *PABC.*

MacMillan Survey

- “Carers assessments and clear support for the carer. Tell them what is and what is not available to them. Health and wellbeing teams to develop to let patients and carers know what there is in their area and how to achieve this help - transport, etc. Isolation is a major issue in the country area I work in. For e.g. getting to Helen Rollason centres. Financial support” *HSC Professional.*
- “Communication needs improvements” *HSC Professional.*
- “Emotional support wasn't offered and I needed this. Also transport”. *PABC*
- “Too early to tell. More testing for at earlier age”. *PABC*
- “GPS to raise awareness of cancer and refer people to support. Jargon in letters from consultant to be avoided and GPS and hospitals to work together and have patients best interest in mind” *PABC.*
- “Staff cuts and increased needs are impacting capacity” *HSC Professional.*
- “More emotional support for person and carers. More awareness of support in GP surgery’s” *PABC.*
- “Testing of men from 50 onwards” *PABC*
- “Ongoing support” *PABC*

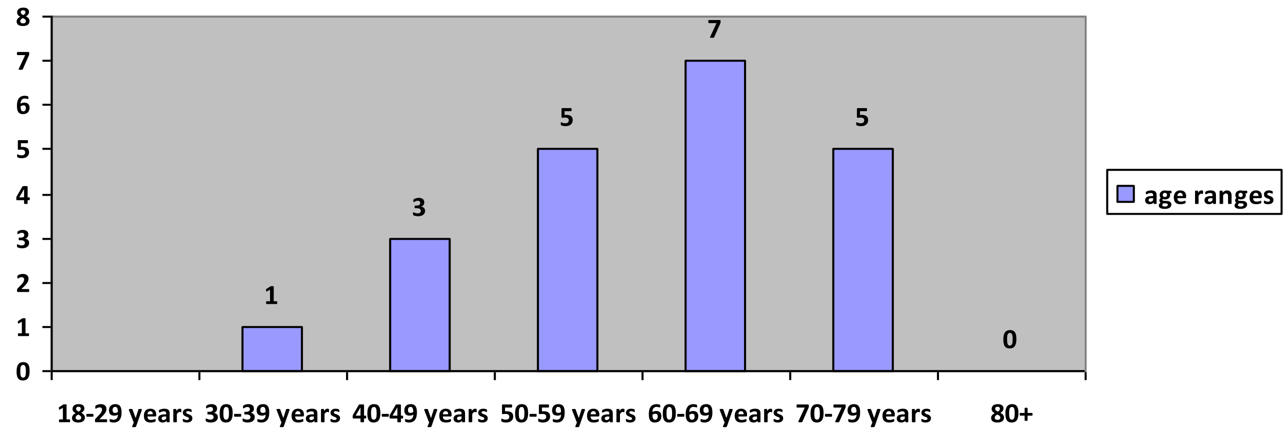
Location of participants:



Participants were from locations within Harlow in West Essex (10), Sawbridgeworth in East Hertfordshire (1), Bishops Stortford in East Hertfordshire (8).

MacMillan Survey

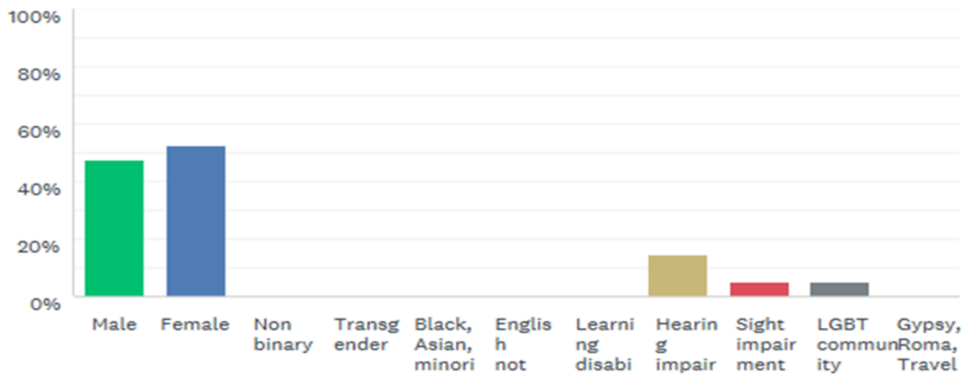
Age Group:



Key indicator: More scoping of the needs of young people and adults.

Diversity within participants

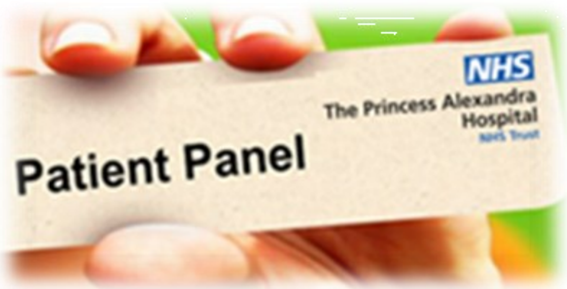
Answered: 21 Skipped: 0

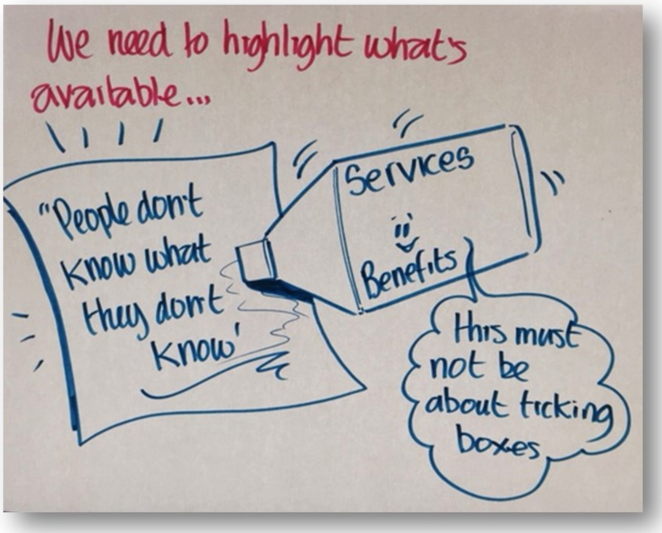


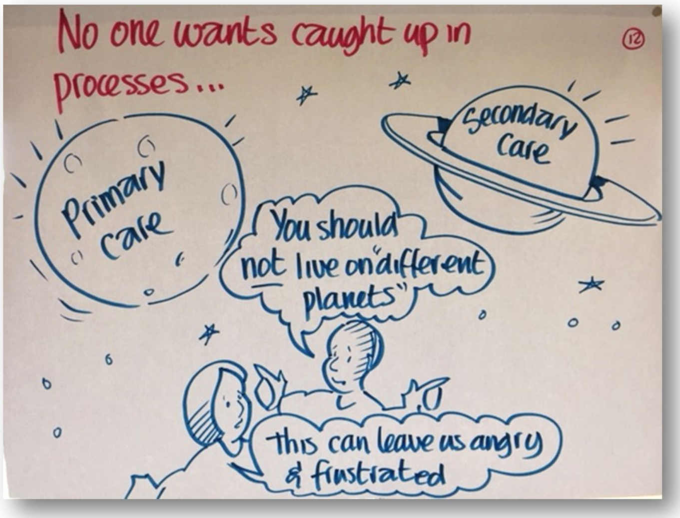
Conclusion and Recommendations:

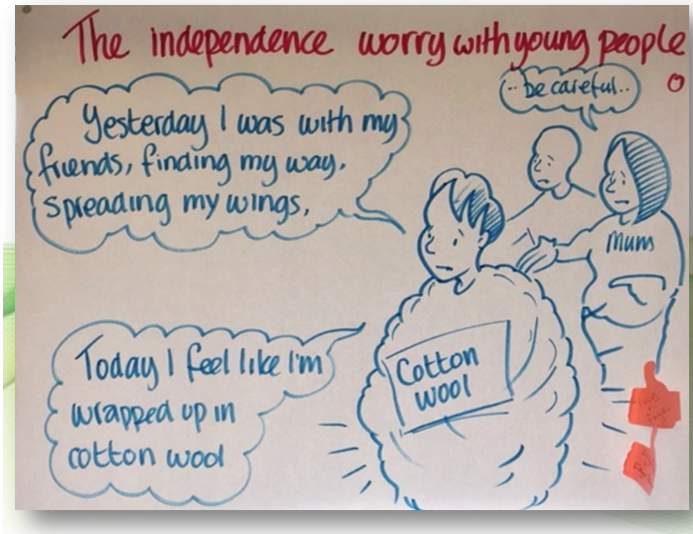
- Improved access and signposting to emotional support, counselling and support groups for PABC, including carers
- Improved access and signposting to welfare benefits advisors
- Improved communication and joined up working between hospital staff, GPs, patients and carers
- Improved opportunities for reviewing holistic needs and signposting to community support, including when treatment has ended
- Macmillan and local cancer services information to be more accessible, through trusts and GP surgeries
- Improved access and signposting to information and support for PABC, including carers
- Transport (ways to decrease travel times and travelling to different hospitals)
- More scoping and relationship building with hard to reach groups, to develop deeper insights of service gaps and improve access

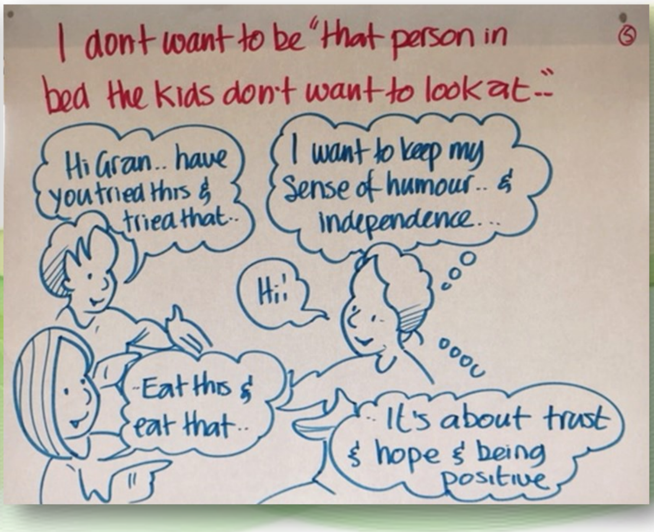
Cartoon Illustrations from the conference



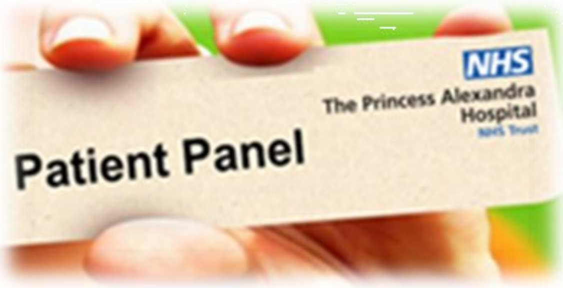


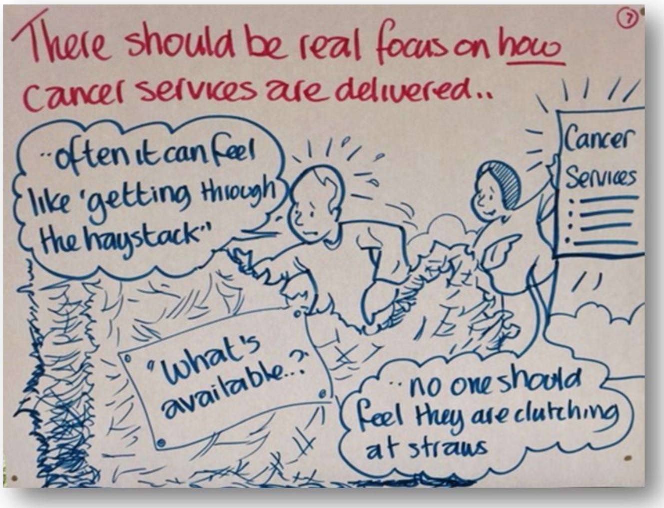


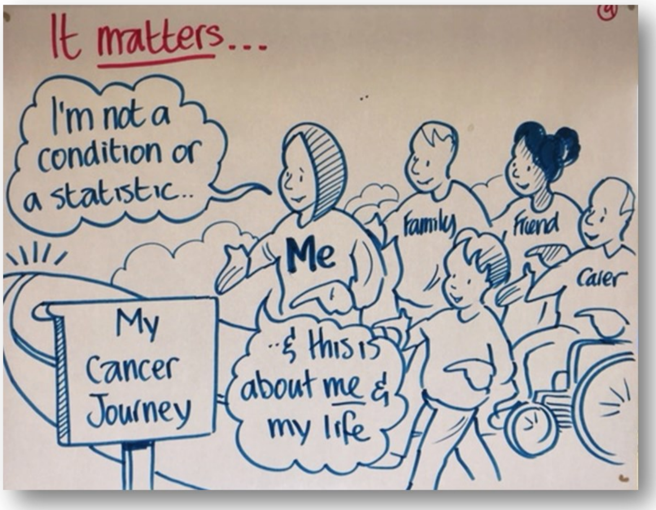


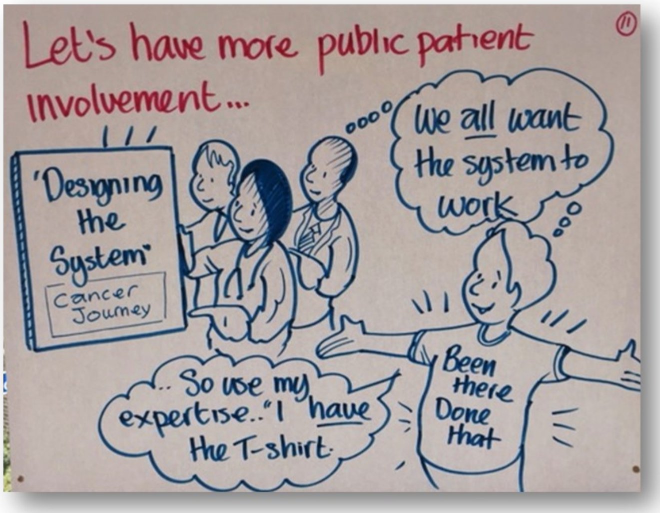


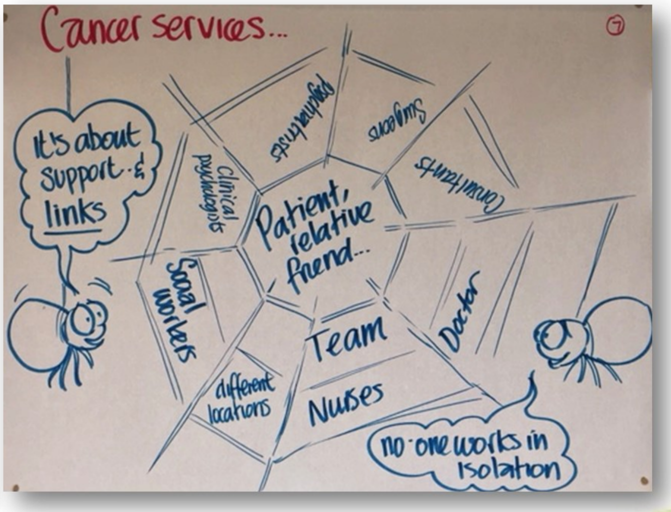
Cartoon Illustrations from the conference

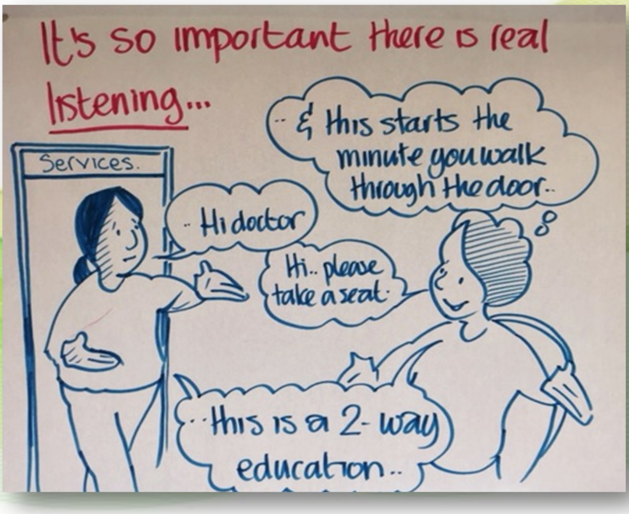




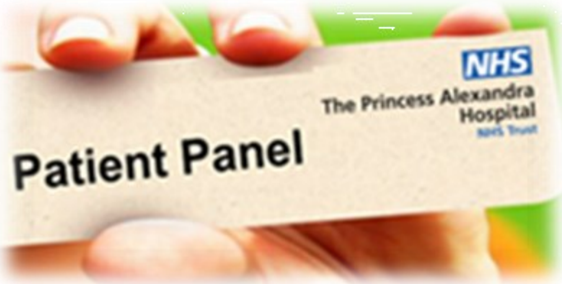


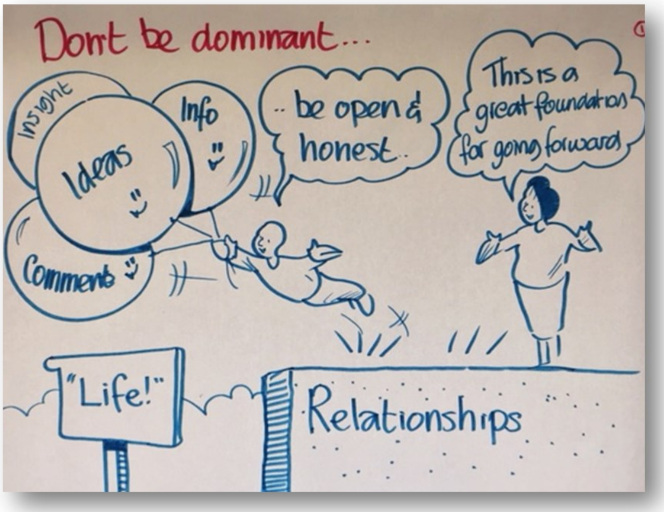


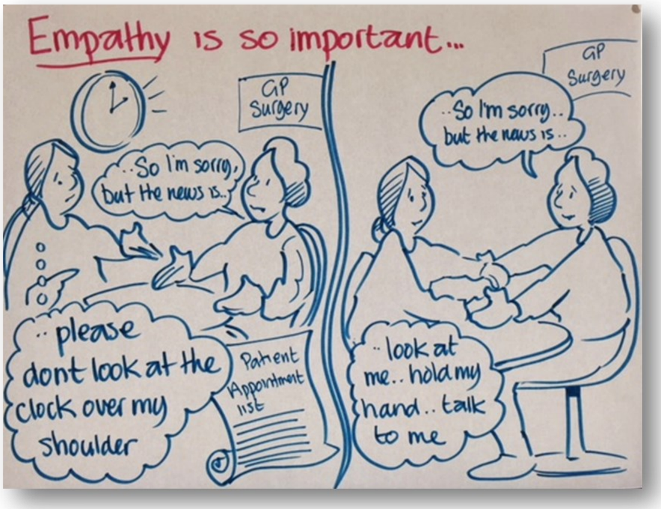


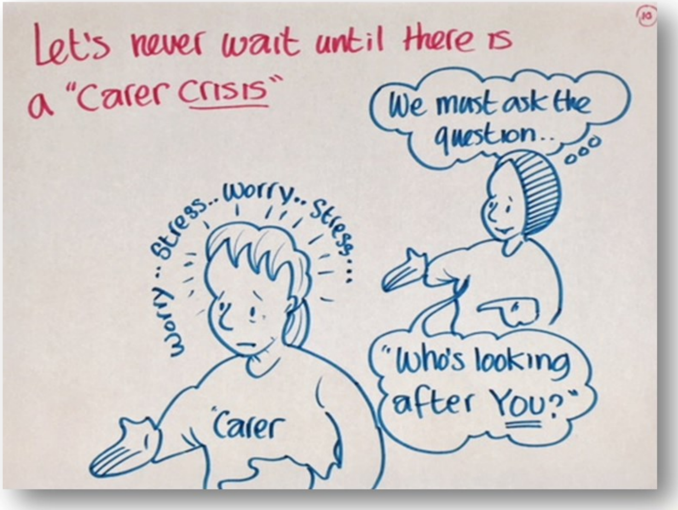


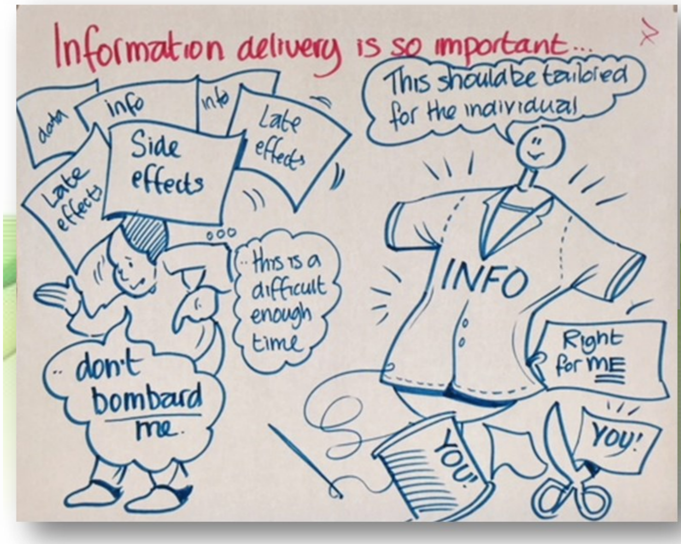
Cartoon Illustrations from the conference

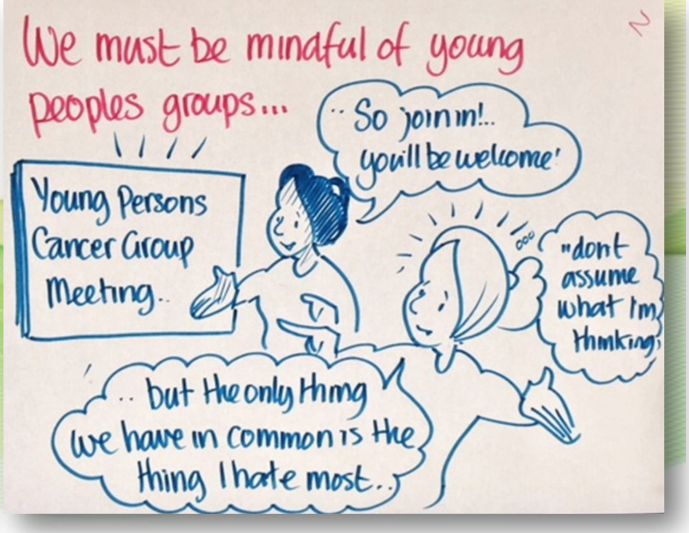


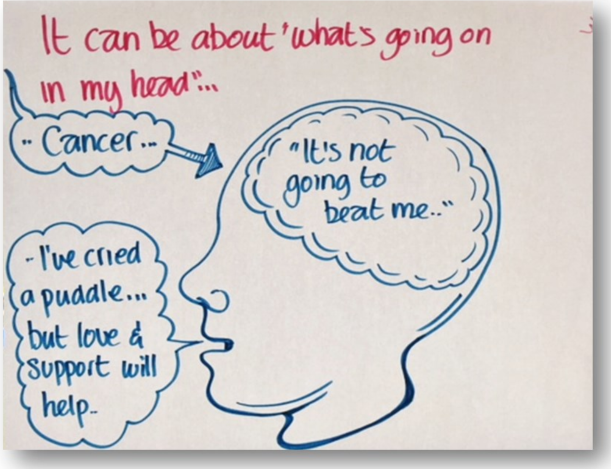


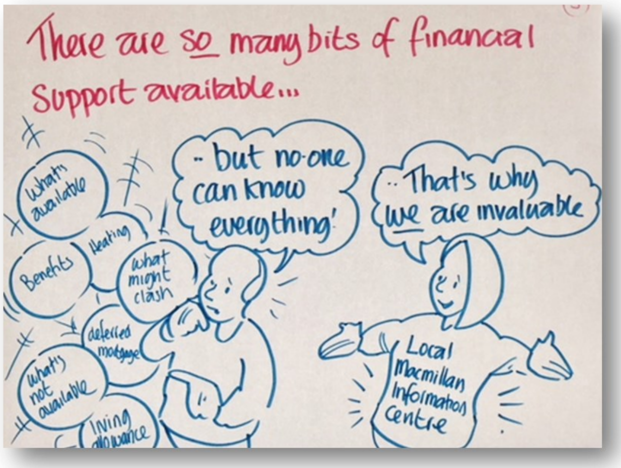


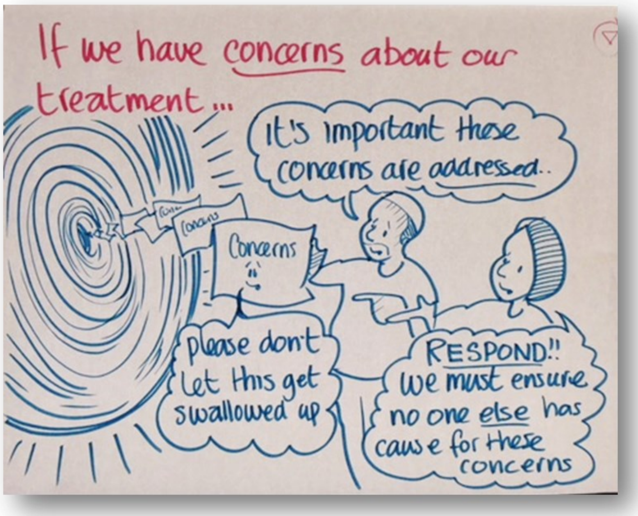






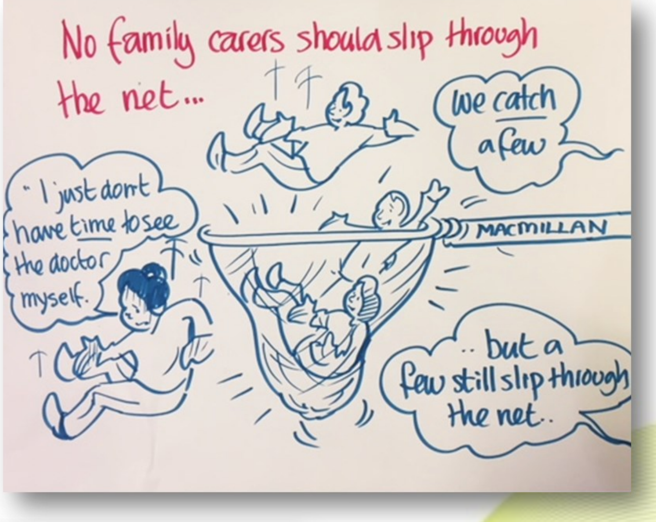

It can be about 'what's going on in my head'...
.. Cancer..
"It's not going to beat me.."
- I've cried a puddle... but love & support will help..

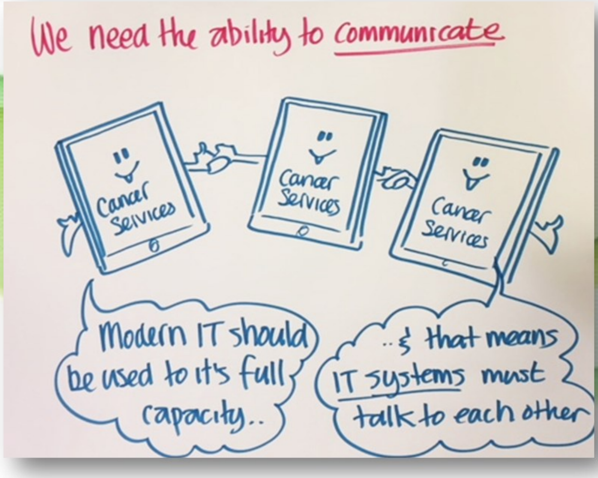

There are so many bits of financial support available...
what's available
Benefits
Heating
what might clash
deferred mortgage
what's not available
living allowance
.. but no-one can know everything!
.. That's why we are invaluable
Local Macmillan Information Centre

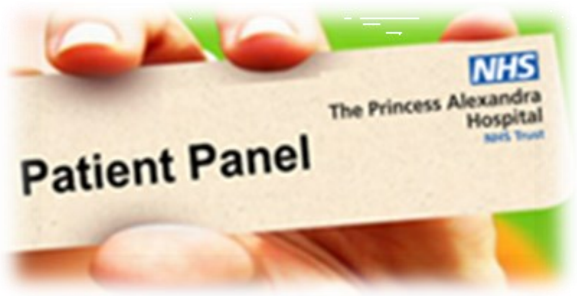

If we have concerns about our treatment...
It's important these concerns are addressed..
Concerns
Concerns
Concerns
please don't let this get swallowed up
RESPOND!! We must ensure no one else has cause for these concerns


We are about spirit, mind & heart...
.. nurture, care for & progress..
Cancer Journey


We need a directory of services...
Cancer Services
who does what
let's have a 1-stop shop 'Yellow pages' of services

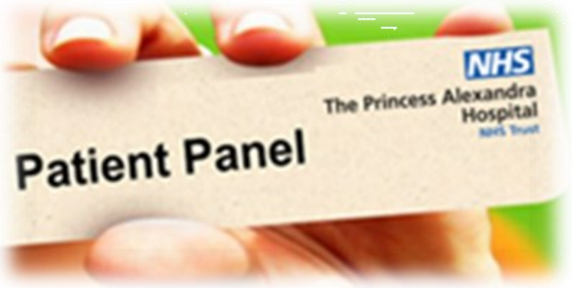

No family carers should slip through the net...
we catch a few
" I just don't have time to see the doctor myself.
MACMILLAN
.. but a few still slip through the net..


We need the ability to communicate
Cancer Services
Cancer Services
Cancer Services
Modern IT should be used to it's full capacity..
.. & that means IT systems must talk to each other



West Essex

The West Essex Macmillan Cancer Information and Support Service 1st Floor, Addison House, Hamstel Road, Harlow, Essex, CM20 1EP Tel: 01279 698 673 Email: west-essex.cancerinformation@nhs.net Web: https://eput.nhs.uk/our-services/west-essex/cancer-support/	Support and information for anyone affected by cancer • Face to face visits to discuss your needs • Information and access to other services • Benefits advice and assistance • A volunteer befriending service • HOPE course – six week self-management course for people living with cancer and who have finished their cancer treatment • Information service at Williams Day Unit, Princess Alexandra Hospital • Information points at St Margaret's Hospital, Epping and Saffron Walden Community Hospital
Macmillan Welfare Benefits Service Delivered by Colchester Borough Council within reach in to hospitals in Essex (service wil begin delivery at Princess Alexandra Hospital in 2018) Tel: 0800 0196003/6065 (24hr answer-phone) Email: Macmillan@colchester.gov.uk	The team can identify eligibility for benefits, assist with completing forms and provide support to challenge unfavorable benefit decisions.

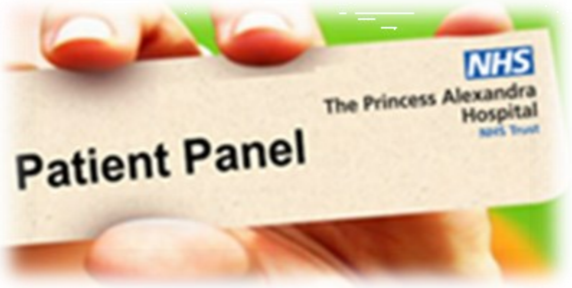


Carers support

Action for Family Carers Tel: 0300 7708090 Email: info@carersinessex.org.uk Web: www.carersinessex.org.uk (referral can be made via the website)	• Provide emotional support, practical support, advice, information and informal advocacy • Includes Macmillan carer support for carers of people with a terminal diagnosis who are approaching the end of life.

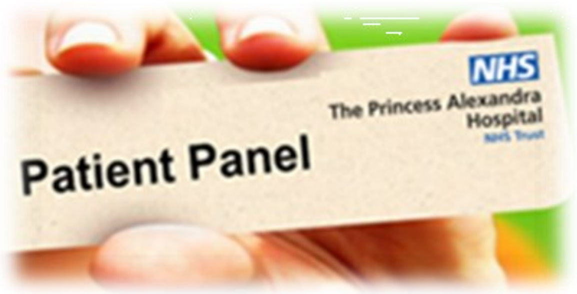
Transport or Parking

Epping Forest Community Transport Tel: 01992 579556 Web: www.vaef.org.uk Operates in your community with volunteer drivers	• Individual bookings • Group bookings • Voluntary/community groups • Community buses • Excursions • No emergency doctor/hospital appointments
Uttlesford Community Travel • Tel: 01371 875787 • Web: www.uttlesfordcommunitytravel.org	• Community volunteer transport for the over 60's the disabled or those who are rurally isolated • The service covers all types of medical appointments, travel to day centers, hair appointments, days out or visits to friends • You will need to become a member to use the service and there is a charge made



Citizens Advice

Uttlesford Citizens Advice Bureau Barnards Yard, Saffron Walden, Essex, CB11 4EB Tel: 01799 618840 Email: bureau@uttlesfordcab.cabnet.org.uk Web: www.uttlefordcab.org.uk	• Advice on housing • Financial advice • Advice on education • Advice on work
Epping Forest District Citizens Advice Bureau Tel: Phone us 03444 770 808, Monday to Friday 10.00 to 16.00 Epping Office - Ernest Wythes House, 50a Hemnall Street, Epping CM16 4LS Loughton Office - Loughton Library (first floor), Traps Hill, Loughton IG10 1HD Waltham Abbey Office - Side Entrance, Town Hall, Waltham Abbey, Essex, EN9 1DE Web: http://www.citizensadviceefd.org.uk/#	• We provide free, confidential and impartial advice and campaign on big issues affecting people's lives. • Advice on housing • Financial advice • Advice on education • Advice on work



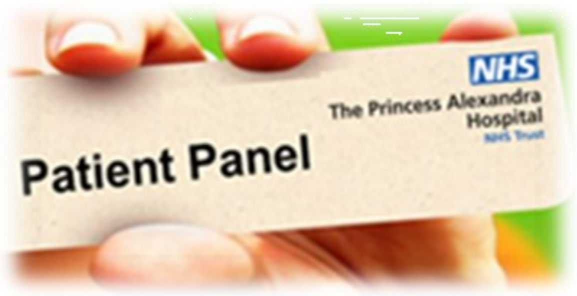
Citizens Advice

Harlow Citizens Advice Bureau 13-15 Eastgate, The High, Harlow, Essex CM20 1HP, open Monday - Friday 10am-4pm Tel: 0344 4770808 Public Telephone Access Line for guidance and information Monday, Wednesday and Friday 10am till 1pm Web :http://www.harlowcitizensadvice.org.uk/	Citizens Advice Harlow gives advice audited by the Citizens Advice Service. All advice is given free of charge but is of the highest professional standard. We deal with a wide range of issues including debt, divorce, benefits, housing, consumer and legal issues.

Bereavement Support

Cruse Bereavement Care Tel: National helpline – 0844 477 9400 Email: helpline@cruse.org.uk Website: www.cruse.org.uk Cruse young people's support Helpline 0808 808 1677 Website www.RD4U.org.uk	• Cruse is a national charity that provides advice, information and support for anyone who has been bereaved, whenever or however the death occurred. • A free confidential service. • Face-to-face, telephone, email and website support, both post- and pre-bereavement. • National helpline and local services throughout the country

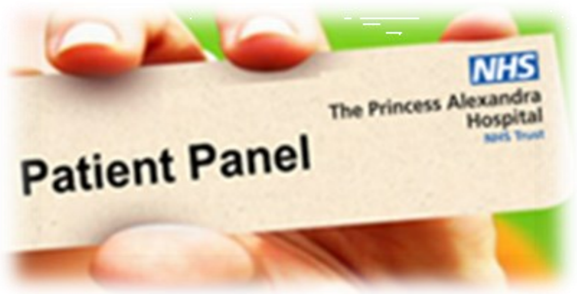
Directory of Cancer Services



Support groups & services

Helen Rollason Herts and Essex Hospital, The Kitwood Suite, Cavell Drive, off Haymeads Lane, Bishop's Stortford, CM23 5JH Tel: 01279 827646 Email: admin@helenrollason.org.uk Web: www.helenrollason.org.uk	• The centre offers a range of free support and therapies to help people living with cancer • Including counselling and support groups • Complementary therapies
The Hummingbird Group Herts and Essex Hospital, The Kitwood Suite, Cavell Drive, off Haymeads Lane, Bishop's Stortford, CM23 5JH Tel: 01279 827247 http://www.hummingbirdgroup.btck.co.uk/	• The centre offers Reiki within NHS environments and other health support groups • Drop in meets on alternate Mondays, 10am to 1pm at the Rhodes Arts Centre Cafe Bar, off South Road in Bishop's Stortford
ProActive – Prostate Cancer Self-Help Group Tel: 07747 374692 Email: proactive.epping@gmail.com Web: www.proactive.me.uk	An informal local group for men with prostate cancer, and their carers, which provides support to other patients and their families through regular meetings at St Margaret's Hospital.

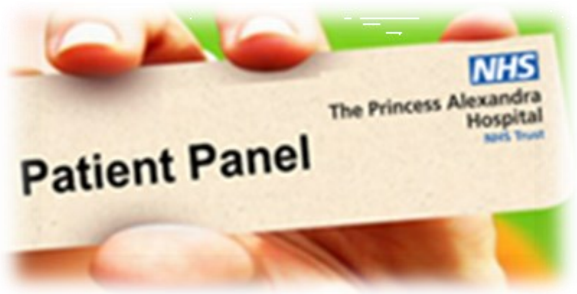
Directory of Cancer Services



Support groups & services

Breast Cancer Support Group Orchard Day Unit, St Margarets Hospital, The Plain, Epping, Essex, CM16 6TN Tel: 01992 575449 (Gloria Eveleigh)	• Advice, peer support & practical help for women who have, or have had, breast cancer. • Meetings are the 3rd Thursday of the month, 7.00pm-8.45pm • Alternate months have information session with a guest speaker. • Patients are encouraged to self-refer
Secondary Breast Cancer Support Group Based at UCLH in London Tel: 020 3906 1406 Web: www.breastcancerhaven.org.uk	• Monthly group specifically for patients with metastatic breast cancer. • Meets monthly on Tuesdays from 5.30pm-7pm
Lung Support Group Paringdon Sports Club, Paringdon Road, Harlow, Essex, CM19 4QT Tel: Tracey Horey (Lung Cancer Nurse Specialist) – 07932526152, 01279 827622	• Peer support for people who are affected by lung cancer: patients, relatives & carers. • Facilitated by Lung Cancer Nurse. • Guest speakers. • Meetings are the 1st Wednesday of the month, 2pm-4pm

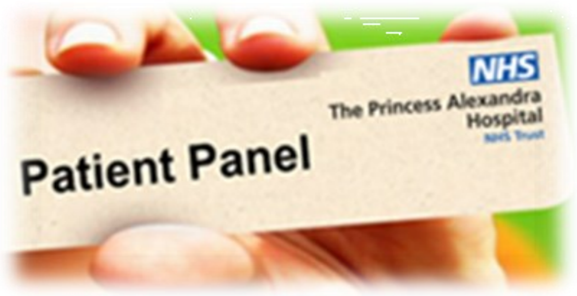
Directory of Cancer Services



Support groups & services

Connect - Stoma patients support group The Harlow & District Stoma Group, The Link, Parsloe Road, Harlow, Essex, CM19 4RT Tel: Lin Hart 01279 505273 Email: comeconnectwithus@gmail.com	• Oesophageal & Gastric Cancer & Related Conditions Support group offering practical & emotional support for stoma patients, partners, family and friends. • Monthly programme of events. • Annual fee £8 single, £13 joint (partner or friend) • Meetings are 2nd Tuesday of every month, 10.30am-12noon
Essex Bowel Cancer Support Group Facebook based online support group Admin: Emma Sly – Macmillan Recovery Package Manager, Princess Alexandra Hospital Tel: 01279 444455 ext 3023 Email: Emma.Sly@pah.nhs.uk https://www.facebook.com/groups/1463159353981457/ (or from your personal Facebook acct. just search for Essex Bowel Cancer Support)	• This is a closed/private support group for anyone affected by Bowel Cancer. • A very friendly bunch who offer peer to peer support for anyone who needs. • The group is overseen by a specialist nurse who can be available for any medical questions
Macmillan Use this link to check for support groups in your local area: https://www.macmillan.org.uk/in-your-area/index.html?latitude=51.767787&longitude=0.087806&location=Harlow&keyword=&radius=30&tridionpromocount=0&nationalorganisationcount=0&nationalresultcount=0&page=1	

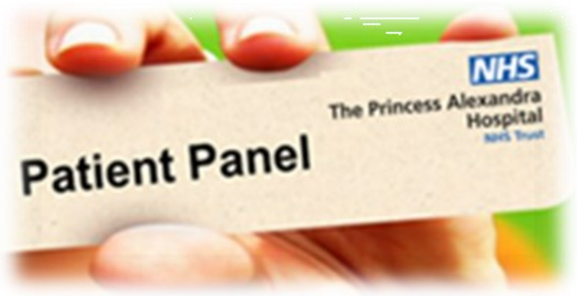
Directory of Cancer Services



Emotional, health & Well-being support

Healthy Minds Tel: 0300 2225943 Web: www.hpft.nhs.uk/healthyminds	• Healthy Minds is a NHS service offering quick and easy access to talking therapies, practical support and employment advice for anyone who may be experiencing depression, anxiety or stress
Health and Wellbeing Events Emma Sly Macmillan Recovery Package Manager Princess Alexandra Hospital Tel: 01279 444455 ext 3023 Mob: 07932 526156 Emai: Emma.Sly@pah.nhs.uk	• Events organised every 3-4 months for patients and their loved ones. The events offer advice on a variety of topics including: • Diet & nutrition, Exercise, Benefits, Breathlessness, Fatigue and Mindfulness • Plus gives an opportunity for peer to peer support
Moving on from your breast cancer (MBV course) Held in either Epping or Harlow Tel: 01279 827857 Email: mbvatpah@outlook.com	• A free course for anyone with breast cancer. • Aimed at self and health improvement post treatment • 2hrs per week for 6 weeks • Incudes sessions on nutrition, physiology, exercise, mindfulness, dressing post treatment. • An opportunity to share experience and learning with other breast cancer patients

Directory of Cancer Services

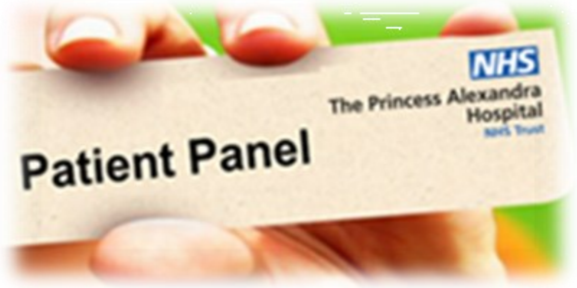


Emotional, health & Well-being support

Fabulous and Beautiful Held in either Epping or Harlow Tel: 01279 827857	• Held first Monday of the month from 11am – 2pm. • Pampering session and chance to talk to other people with breast cancer
Macmillan Hope Course Run by The West Essex Macmillan Cancer Information and Support Service Tel: 01279 698 673	• HOPE course is a six week self-management course for people living with cancer and/or who have finished their cancer treatment

Physical activity

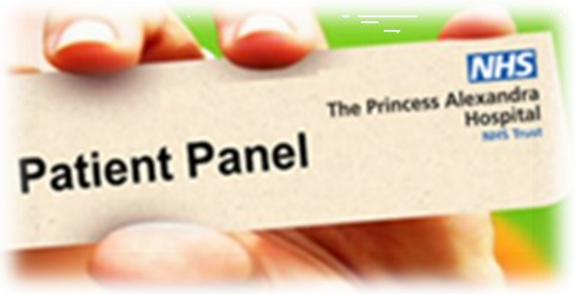
Cancer Be Fit – Fitness for breast cancer survivors Tel: 07701 094373 Email: elaine@tayloredfitness.co.uk	• A free fitness class run by Elaine, a survivor and qualified Cancer and Exercise Rehabilitation Specialist • Classes on Tuesdays 10.30am at The Norman Booth Centre, Elderfield, Mulberry Green, Old Harlow, Harlow, CM17 0EY
Active Harlow Social Strollers Tel: Chris Purvis - 01279 446435 Email: chris.purvis@harlow.gov.uk	• Walks are free to join and happen every other Friday in Harlow Town Park. • A calendar of our walks is available at www.harlow.gov.uk. • 30 minute or 60 minute route option available.
An introduction to physical activity Held at either Epping or Harlow Contact Ruth McCrea Tel: 01279 827395 (Wed – Thurs 9am-5pm) Email: Ruth.Mccrea@pah.nhs.uk	• A free course for anyone with breast cancer who wishes to improve their level of exercise post treatment • A fun six week course • 12.30-1.30om on Wednesday • All levels of fitness welcome even if you have never exercised before



Physical activity

Move More Herts Tel: 01727 731540 Web: oneymca.org/movemoreherts Email: movemoreherts@oneymca.org	• A programme for anyone affected by cancer to help them become and stay more active. • 12 weeks free funded activity sessions • Instructor guidance and support for up to 12 months • ‘Plus one’ membership available • Self-referral or referral via a health/ social care professional
Energise Cancer Rehab Epping Sports Centre, 25 Hemnall Street, Epping, CM16 4LU Tel: Annette Stansfield (Cancer rehabilitation scheme coordinator) – 01992 564564 Email: annettestansfield@everyoneactive.com	• 12 week programme with advice and support to becoming more active • Referral via GP or health professional • 12 weeks of unlimited exercise for £49.95 • Cancer rehab exercise class runs on Monday 12.30pm – 1.45pm, which is free while on the scheme • Personal health assessment and exercise programme • Nutritional. Exercise and lifestyle support • Online activity planner • Specialist cancer rehab classes • Low impact classes including yoga, pilates and stretch • Swimming

Directory of Cancer Services



Hospice

St Clare Hospice St Clare Hospice, Hastingwood Road, Hastingwood, Essex, CM17 9JX Tel: 01279 773 700 Web: http://stclarehospice.org.uk/ Email: info@stclarehospice.org.uk	• St Clare Hospice is a local charity and each year we care for hundreds of people across West Essex and the East Hertfordshire border. • Provide free, compassionate care and support to adults with life-limiting illnesses, their families and carers.

Practical Support

Community Agents Essex – Supporting Independent Living Tel: to arrange a free visit, call 08009 775858 or 01376 574341 Web: www.communityagentessex.org.uk Email: enquiries@caessex.org.uk	• An innovative partnership supporting older people over 65 and their informal carers • Mobility issues • Practical living skills • Social inclusion • Healthy living • Caring for someone • Individual resilience

Lymphedema Support

Referrals via GP. Breast cancer referrals are sent to Breast Care Unit, St Margaret's Hospital. Non breast patients are sent to HCCT via Chloe Atkinson at WECCG.	The service is community based and was established to treat people affected by lymphedema secondary to their cancer. It also cares for patients who have complex oedema at end of life.