



Scotland's Patient Experience Programme

CANCER PILOT UPDATE - MARCH 2010

Three cancer pilots are being supported through the work of Better Together. Please find March update below.

NHS Grampian

The Grampian pilot commenced in September 2009 – initial objectives for the first six months have been met.

- Project Team, Project Steering Group and office base set up
- Project initiation document including risk plan and communication plan agreed
- Assessment of inequalities in local cancer services to inform the prioritising of issues which the Grampian pilot should focus on has recently been completed
- Developed and piloted patient experience tools including patient feedback log, staff log, patient interviews in the Haematology Clinic at Aberdeen Royal Infirmary
- Patient and Carer Reference group set up and has met twice. This group is advising the project on the best approaches for gathering patient experience information and on questionnaire design.
- Developing and piloting a set of patient experience technique cards for staff to build up skills in patient experience work (in conjunction with Nurse Consultant for Patient Experience)

The Project Steering Group has agreed 6 project areas. These will be further developed into patient experience projects over the course of the pilot:

- Poor uptake of national screening programmes in populations and areas associated with higher levels of deprivation
- Chemotherapy services with a focus on patients who live in remote and rural and more disadvantaged communities
- Upper GI and Head & Neck cancers
- Radiotherapy treatment (Aberdeen is the regional centre for Grampian, Orkney and Shetland patients) supporting staff in that service to conduct their own patient experience work
- In-patient services – including patients who are cared for in wards outwith the ANCHOR Unit (main oncology & haematology wards)
- Haematology Clinic services

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NHS Lothian

Neuro-oncology Teenage and Young Adult Transition:

This project sought to explore, understand and improve the experiences of teenage and young adult patients during the transition from paediatric to adult neuro-oncology services in Lothian. The first phase of the project utilised a range of methods to capture the experiences of patients, parents, and

staff. An improvement workout was held in December 2010 involving a range of staff from both children's and adult services. During this event experience information was feedback to staff who were supported to then develop an ideal vision for a managed transition process and related action plan for implementation.

The second phase of this project will be undertaken in 2011 which will focus on review and refinement of improvement activities. An interim evaluation has been performed and has generated learning points for use in other projects.

Head and Neck Cancer: Experience at all stages of the head and neck service pathway of patients with cancer of the larynx, lip, oral cavity and pharynx will be explored. Particular efforts will be made to engage patients from South East Asian and socio-economically deprived backgrounds. This project is being co-delivered with a third party 'Think Public' who have undertaken Experience Based Design work in England. Think Public will train staff in the methods that they use and will facilitate the evidence review and rapid improvement events. Detailed planning for this will take place in early April, with project being delivered over the summer/autumn.

Learning disabilities: The first phase of this work (runs until August 2010) includes review of literature, gathering the experience evidence of staff working in cancer services, auditing services against the Lothian action plan on learning disabilities to identify focus areas and planning the actions for further experience gathering and improvement activity in phase 2.

Chemotherapy services: This work is planned for 2011. It is envisaged that local staff skilled in patient experience gathering (from the Compassionate Care programme) will be used to support projects in out patient and in patient chemotherapy.

Other: In addition to discrete project work, the programme has offered training in a range of experience gathering methods to 6 staff from a range of clinical backgrounds. This is currently underway. The project team has also engaged with staff at a variety of fora to facilitate experience gathering.

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West of Scotland

The pilot approach, methodology and data collection tools, i.e. consent and equalities monitoring forms have been agreed with the West of Scotland Research Ethics Committee and the information governance department in NHS GGC. The project did not have to go through formal ethics as it was classed as service evaluation. A steering committee has been formed to oversee the pilot and this includes representation from each of the health boards and WoSCAN. The priorities for the first round of projects were agreed as day case chemotherapy, bowel screening and colorectal cancer. Priorities for the second round of projects are currently being discussed and agreed with local health boards.

Focus groups were carried out last July in Glasgow to capture 'harder to reach' groups views on the proposals for the national bowel screening DVD. A report and local action plan are available. Six patient experiences projects are underway and four of these have began capturing patient, carer and staff experiences. To date over 120 participants have been recruited to share their experiences of cancer services across the four health boards in the west of Scotland and at the Beatson West of Scotland Cancer Centre. The services involved differ in each health board and include day case chemotherapy, colorectal cancer, lung cancer & nurse/pharmacy led chemotherapy services. In addition, an outreach recruitment programme is being piloted across Greater Glasgow and Clyde with existing community and voluntary groups.

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For more information on Better Together, Visit our website today on www.bettertogetherscotland.com