



National Cancer Survivorship Initiative

Living With and Beyond Cancer: The Children & Young People Work-stream

Sheffield Test Centre Report

October 2010

Partner organisations

North Trent Cancer Network
Sheffield Teaching Hospitals NHS Foundation Trust
Sheffield Children's Hospital NHS Trust
Academic Units of Clinical Oncology, Endocrinology & Supportive Care
University of Sheffield
Late Effects Group, Sheffield
Sheffield PCT
Yorkshire & Humber SCG
CLIC Sargent
Macmillan Cancer Support
Royal College of Nursing
Teenage Cancer Trust

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ACRONYMS/abbreviations

C&YP	Children and Young People
CAT	Cancer Action Team
CNS	Clinical Nurse Specialist
CS	Cancer Survivor
CSC	Cancer Support Centre
DNA	Did Not Attend
EOT	End of Treatment
FU	Follow-up
GP	General Practitioner
HCW	Health Care Worker
HCP	Health Care Professional
IOG	Improving Outcomes Guidance
LE	Late Effects
LEC	Late Effect Clinic
MDT	Multi Disciplinary Team
NCSI	National Cancer Survivorship Initiative
NICE	National Institute for Health and Clinical Excellence
NTCN	North Trent Cancer Network
Onc	Consultant Oncologist
Paed	Paediatric oncologist/paediatrician
PS	Project Support
PCT	Primary Care Trust
PTC	Principle Treatment Centre
RCN	Royal College of Nursing
RHH	Royal Hallamshire Hospital
SCG	Specialised Commissioning Group
SCH	Sheffield Children's Hospital
STH	Sheffield Teaching Hospitals
TCU	Teenage Cancer Unit
TYA	Teenage and Young Adult
WPH	Weston Park Hospital
YP	Young Person/People

Scope and focus of Sheffield proposal

The service improvement and evaluation projects presented in this report were commissioned as part of the National Cancer Survivorship (NCSI) Initiative's Children & Young People Work-stream. They have been funded by an award from NHS Improvement in partnership with Macmillan Cancer Support and North Trent Cancer Network (NTCN).

In Sheffield, our programme of work has been supported by both the North Trent Cancer Network and the Yorkshire and the Humber Specialised Commissioning Group (SCG). The programme of work was included in the Network wide action plan approved by local SCG. Most of our projects build on our efforts to implement the recommendations of the NICE Children & Young People's Improving Outcomes Guidance (C&YP IOG).

In practice, our programme of service improvement pilots have been driven through the Multi Disciplinary Teams (MDT) responsible for coordinating care: the Teenage & Young Adult (TYA) MDT and the Late Effects (LE) MDT. Teamwork has been essential. We would particularly like to acknowledge our service users (the patients) Tom Grew, Lauren Stone and James Ashton) who contributed enormously to the planning and execution of our projects. Other key people include the five working group leads: Hayley Williams; Philomena Scott; Judith Bird; Dr Kevin Bolster; Jan Siddall and Gail Peacock (Programme Support). Each of the working group's membership is listed in the report.

The synopsis of each project is deliberately brief. More substantial reports are available on request.

Apart from service improvements, this proposal includes workforce initiatives with the intention that we contribute to the understanding of what skills and knowledge are required in the workforce for delivery of appropriate care for young cancer survivors. This, our largest and most ambitious project, is ongoing at the time of this report. It is scheduled for completion in April 2011. The results reported here are from the first phase of this project.

This report summarises our work completed by August 2010.

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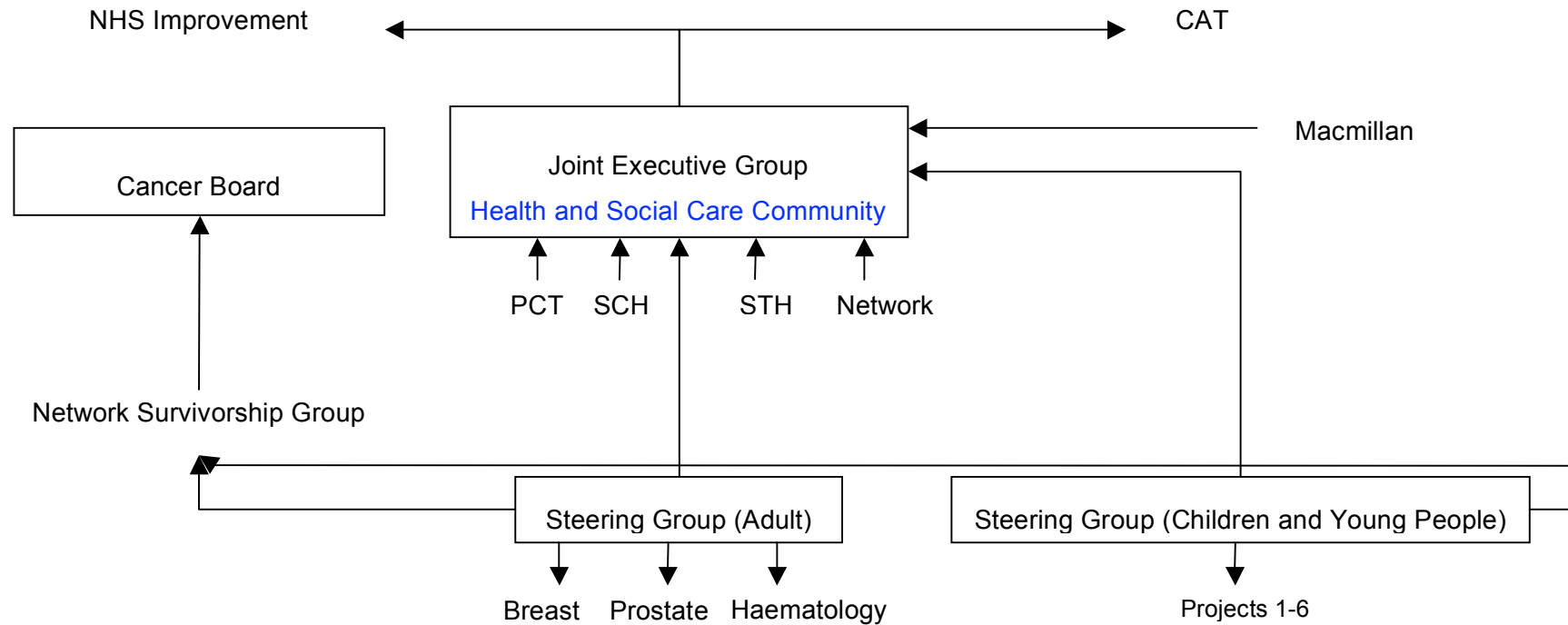
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on behalf of the Sheffield CYP Test Centre

October 5th 2010

Sheffield Cancer Survivorship Test Communities Accountability Structure



Test site management and reporting systems: The Executive Group provided governance support for both the CYP and Adult survivorship programmes. The individual project working groups and steering groups differed.

Project 1: Telephone reminder system to improve “Did Not Attend” rate at the Late Effects Clinic

Why?

- To reduce wasted appointments
- To ensure higher number of patients received planned follow-up care

Aim:

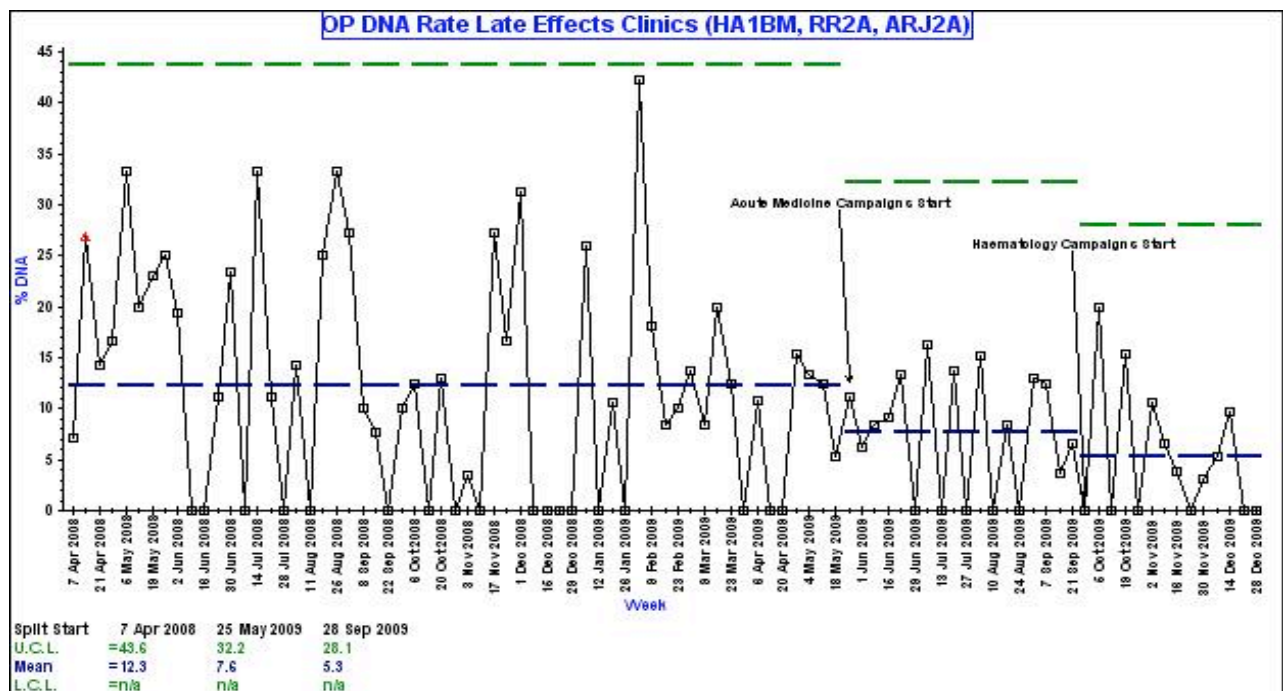
- To improve Did Not Attend (DNA) rate at our Late Effects Clinic (LEC).

How?

- Monitored DNA rates at LEC before and after the intervention
- Using the system Remind+ provided by Telephonetics VIP

Results:

- Prior to the intervention our mean DNA rate was 12.3% but was highly variable and we could only be confident (to 3 Standard Deviation) that it would not be above 44%.
- The DNA (not cancellations) rate dropped from 120 missed appointments to about 60 missed appointments, i.e. 60 more cancer survivors received planned care. This was based on a full year and is the difference between the 2 DNA rates applied to the number of total appointments in that period.
- The interventions happened in 2 stages and now the mean DNA rate is currently 5.3% and we can be confident that it will not go above 28%.
- Financially the LEC recovered ~ £6-7k in otherwise lost tariffs.
- Overall the mean DNA rate reduced by >50%.



Limitations:

- Insufficient preparation and engagement of patients
- Options for an opt out facility
- Text messaging preferred

Implications:

- Financially the LEC recovered ~ £6-7k in otherwise lost tariffs.
- Implementation costs for the Trust are in the order of £80k. Revenue cost is around £50k per annum but is volume dependent. The Trust on a whole have had an increased income of £1.4 million.
- Young people prefer a text reminder rather than automated voice reminder and we would like to revisit the possibility of implementing this.

Working Group

Hayley Williams	Cancer Manager, STH and Project Lead
Paul Harriman	Assistant Director, Service Improvement
Denise Friend	Programme Manager, NTCN
Gail Peacock	Project Support, NTCN
Diana Greenfield	Macmillan Nurse Consultant & CYP Test Centre Lead

Project 2: Transition of late effects care: Young people and parent's views of best practice

Why?

- Existing evidence suggests that having an effective transition process from paediatric to adult services is vital to the future of the health of the young cancer survivor.

Aim:

- To formally evaluate our existing transition service for childhood cancer survivors and identify areas for improvement.

How?

- 19 young cancer survivors (CS) and 23 parents (P) recently transitioned from the paediatric setting were recruited by post and from the Late Effects Clinic.
- The questionnaire (2 versions: patient and parent) comprised four sections (25 items) exploring information transfer; clinic organisation, access and environment; experience with hospital staff; transition process.

Results:

- 13/19 CS and 17/23 P considered the timing of the move from paediatric to adult services appropriate.
- Provision of written information was helpful (19= CS, 23 = P). 4 CS requested more comprehensive information about the transition process.
- Access to a key worker or treatment summaries had not been made available for everyone (7/19 CS, 16/23 P and 5/19 CS, 4/23 P respectively).
- 13/19 CS and 16/23 P were happy with the waiting room although suggestions were made to improve the décor and make it more age appropriate.

Implications:

- Revision of the transition process, including the provision of information materials should involve service users.
- Giving and recording of information in a variety of formats is important.
- Offering a visit to the adult hospital would be helpful. Improving access to, and knowledge of, a key worker as routine.
- Ensuring the clinic environment is age-appropriate and reflects the needs of service users.
- Reviewing holistic needs as routine following transfer to adult hospital.
- Reviewing the transition strategy to include a process to adult clinicians after transfer.

Working Group

Philomena Scott	Lead Nurse for Children and Young People, STH and Project Lead
Jane Fearnside	Late Effects Research Associate, Cancer Research Centre, STH
Tanya Urquhart	Macmillan CNS Long Term Follow Up/ Late Effects, SCH
Lauren Stones	Service User
Annie Collins	CLIC Sargent Social Worker
Tracy Bayley	Consultant Clinical Psychologist,
Anna Jenkins	Consultant Paediatric Oncologist, SCH
Judi Tapp	National Improvement Lead for C&YP Survivorship
Denise Friend	Programme Manager, NTCN
Gail Peacock	Project Support, NTCN
Diana Greenfield	Macmillan Nurse Consultant & CYP Test Centre Lead

Project 3: Low risk survivors: Acceptability of low intervention follow-up and supportive care

Why?

- It is unclear how low risk survivors of cancer in young people find their experience of long term follow-up (FU) services.
- Although medically stable, this population may have further supportive care needs.

Aim:

- To determine this satisfaction and to establish any unmet supportive care needs in low risk cancer survivors.

How?

- Young adult cancer survivors were identified from the late effects, teratoma (germ cell) and lymphoma clinics within our Trust.
- Criteria for inclusion were: <25 at diagnosis of cancer, low risk of recurrence or late effects, annual/less frequent FU, and medically stable.
- Patients were surveyed by telephone by a psychology assistant.

Results:

- 25 patients were recruited (100% uptake rate).
- The mean time since treatment was 12 years.
- Some cancer survivors were not clear which clinic they attended and for what purpose.
- Cancer survivors on FU were satisfied with the supportive care received.
- 19/25 had enough information about the long term risks of cancer.
- 14/25 did not feel comfortable with the prospect of discharge.
- 23/25 had the right amount of contact with the FU clinic, and could talk to their GP about a range of issues.
- 22/25 had alternative sources of support for social or emotional concerns.

Implications:

- Clinic letters need revision to ensure they are accurate re who they are seeing and specialty.
- Cancer survivors from our centre on long term FU appear not to have supportive care needs.
- Our findings may have been influenced by time since treatment and those who have already disengaged from FU.
- Supportive care needs both following transition to FU after the end of treatment and in those who have left FU, need to be examined in future work.
- Consideration of alternative models of care including telephone follow-up, preparation for self-management and eventual discharge.

Working group:

Judith Bird	NTCN Lead Nurse and Project Lead
Tanya Urquhart	Macmillan CNS Long Term Follow Up/ Late Effects, SCH
Tom Grew	Service User
Annie Collins	CLIC Sargent Social Worker
Rachel Marfleet	Clinical Psychologist, SCH
Dawn Roe	Clinical Psychology Assistant, SCH
Pauline Pledge	Matron, Weston Park Hospital Outpatient Department
Judi Tapp	National Improvement Lead for C&YP Survivorship
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Project 5: GPs' views on the acceptability & usefulness of treatment summaries and care plans

Why?

- Sharing effective care plans with GP's is one area, identified by the C&YP Survivorship initiative, that might improve the quality of care.
- It may also enable care to be delivered closer to home.
- Our late effects service has been using care plans for many years.
- We were curious about how GPs perceive our care plans and how useful they are in primary care.

Aims:

- To establish how useful late effects care plans are to GPs in conveying treatment summaries, late effects risk, monitoring and health needs of individual cancer survivors.
- To identify areas where GP's would feel confident to manage patients safely and appropriately during survivorship.
- To recommend principles for shared care.

How?

- We worked with the Academic Unit of Primary Care to develop our plan.
- We developed a short survey and used example care plans of patients with minimal, moderate and complex needs.
- We evaluated GP's views by writing to targeted GPs across our Cancer Network and through an electronic link through the Sheffield PCT electronic mailing.
- We asked GPs to respond to the usefulness of the 3 main components of the post treatment care plans (treatment summary, risk profile, proposed management plans).
- We asked GP's to identify areas of care which they would be confident to manage.
- We used example care plans to stimulate thinking.

Results:

- 15/19 targeted GPs responded.
- GPs found all the information in the test care plan useful. Many felt that this level of clinical information is essential to provide good quality care of cancer survivors.
- GP's were generally willing, and expressed a reasonable level of confidence about managing follow-up and surveillance of cancer survivors but wanted good clinical information and clarity about what is expected of them.
- GPs were concerned about taking on follow-up and 'shared care' unless arrangements were properly negotiated and agreed.

Implications:

- The development of an improved treatment summary and care plan will allow for more consistency and continuity of care at a local level improving the quality for patients.
- The evidence highlights the importance of quality clinical information being effectively transferred into primary care. If this is to happen consistently then quality administrative support for specialist clinicians becomes an important issue that commissioners must be mindful of.

- Explore potential pathways for different risk stratified groups. Shifting care for low risk patients into the community may provide a cost efficiency for commissioners (this will need to be modelled based upon which elements of care would be moved and the impact on primary care services and associated costs versus loss of activity in the acute setting) and release of capacity for Trusts (would need to evaluate how many patients are currently seen in the acute setting that could be managed in primary care and how many clinic slots/ other activity this may release).
- Consider development of shared care using principles of best practice already established.
- Present proposed ideas for discussion with the CYP Yorkshire & Humber Site Specific Group.

Working group:

Kevin Bolster	Specialist Doctor in Palliative Care and Macmillan GP Facilitator (Rotherham, Hospice) and Project Lead
Tom Grew	Service User
Anna Jenkins	Consultant Paediatric Oncologist, SCH
Anthony Gore	Primary Care Cancer Lead Clinician, NHS Sheffield
Judi Tapp	National Improvement Lead for C&YP Survivorship
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Project 6: Nurse competences for late effects. Phase 1: the clinician and manager's perspectives

Why?

- Following improved curative treatments in young people's cancers, the NICE Children's and Young Peoples Improving Outcome Guidance (CYP IOG) identified Long Term Follow up Care (LTFC) as a key requirement for service delivery.
- Currently very few centres nationally have a late effects service.
- Given the broad nature of the consequences of cancer treatments, the provision of late effects services will require the range of skills represented within a multi-disciplinary team.
- Those who provide this service will require skills, knowledge and expertise to be able to do so.
- As yet, the skills and expertise that might be required for nurses working within these services has not been systematically clarified or agreed.

Aims:

- To identify the range of skills and expertise that could well be required by nurses who are involved in providing late effects care for this client group from a clinician and management perspective (Phase 1).
- To identify the range of skills and expertise that is being, and would like to be provided by nurses who are involved in providing late effects care for this client group (Phase 2).
- To develop a competency framework for nurses carrying out these roles (Phase 3).

How?

- This is a 3 phase project focusing on the role of the nurse in the provision of late effects care for young people diagnosed with cancer under the age of 25.
- A descriptive survey design was adopted using structured questionnaires.
- This enabled the collection of views of those involved in developing and providing late effects follow up services.
- This process identified 12 core nursing roles that were potentially important to the nurse working in late effects.

Results:

- Skills and levels of responsibility were identified for each of the core roles.
- A total of 80 questionnaires were returned completed.
- An emerging ideal role is presented in Figure 1.

Implications:

- The emerging ideal role of the nurse involved in late effects care would work alongside clinicians, would contribute to the development of the local service at a local level, and importantly, work as part of a multi-disciplinary team.
- Amongst many duties, the nurse would be involved in running nurse-led clinics for assessing patients, provide care according to agreed protocols, provide psychological support and contribute to the development of patient services.
- This emerging role provides insight into managers and clinicians perspectives of nurses providing care in this clinical field.
- The responsibilities presented give only one perspective. The next stage of the project (phase two) is to determine the views of nurses currently providing late

effects care to children and young people. These additional views should help to provide a robust content for the competency framework.

- Phase 3 involves matching responsibilities against the KSF and final endorsement from the RCN.

Working group

Jan Siddall	Nurse Lead for Teenagers and Young Adults with Cancer, STH and Project Lead
Clare Warnock	Practice Development Sister, STH, and Deputy Project Lead
Tanya Urquhart	Macmillan CNS Long Term Follow Up/ Late Effects, SCH
Anna Jenkins	Consultant Paediatric Oncologist, SCH
Judi Tapp	National Improvement Lead for C&YP Survivorship
Maxine Astley-Pepper	Macmillan Development Manager
Sam Debbage	Practice Development Manager, STH
Alison Pass	Service User
Denise Friend	Programme Manager, NTCN
Gail Peacock	Project Support, NTCN
Diana Greenfield	Macmillan Nurse Consultant & CYP Test Centre Lead

Figure one: The potential “ideal” nurses role: the items selected most frequently in each role component.

The potential “ideal” nurses role
Assessment
<ul style="list-style-type: none"> ▪ Review and assess patients independently and then consult with clinician ▪ Nurse led clinics with clinicians present for consultation in clinic area if needed
Tests and investigations
<ul style="list-style-type: none"> ▪ Order tests and investigations according to agreed set protocols ▪ Review test results of patient in consultation with clinician
Late effects surveillance and treatment plans
<ul style="list-style-type: none"> ▪ Create a treatment summary for patients using case notes and referral form for reviewing at a Late Effects MDT as appropriate ▪ Create a potential plan of care for patients using patient summaries, case notes, protocols and/or risk profile and presenting it to Late Effects MDT as appropriate ▪ Create treatment plans with patient according to agreed late effect guidelines and protocols
Self care management
<ul style="list-style-type: none"> ▪ Offer patients leaflets and support literature regarding late effects complications ▪ Discuss potential late effect complications with patient ▪ Provide information about late effects care that requires advanced knowledge ▪ Teach patient to carry out self monitoring and mentor them in the process ▪ Provide general patient information on care issues, treatments and services ▪ Help provide planned programme/education to patients
Medications
<ul style="list-style-type: none"> ▪ Explain medications to patients/carers ▪ Review medication and consult with clinician regarding changes
Referring to others - no comments
Communication skills
<ul style="list-style-type: none"> ▪ Provide psychological support to patients ▪ Facilitate carer support group/s
Follow up care
<ul style="list-style-type: none"> ▪ Telephone consultations with patients as part of planned follow up care (planned and directed)
Organisational structure
<ul style="list-style-type: none"> ▪ Attend Late Effects Multidisciplinary Team Meeting (MDT) ▪ Present patients at MDT
Managing patient services
<ul style="list-style-type: none"> ▪ Represent the service at local meetings in speciality ▪ Represent the service at local strategic meetings ▪ Contribute to the development of protocols/clinical guidelines as part of a team ▪ Contribute to creating service reports ▪ Contribute to the development of business cases as part of a team
Teaching and training and research
<ul style="list-style-type: none"> ▪ Teach groups of Health Care Workers (HCW) and for Health care professionals (HCP) for local service ▪ Teach on externally run educational programmes e.g. university lectures ▪ Create local and network educational programmes for other HCW and HCP
Audit and service evaluation
<ul style="list-style-type: none"> ▪ Contribute to development of audit, service review and/or research in own area ▪ Lead projects for audit and service review ▪ Write for publication on own specialty e.g. article in nursing journals on aspect of care ▪ Collect data required for service evaluation, audit or research ▪ Present abstracts / presentations at conferences

Notes

