ITEM NO: 85.00

TITLE	**LINk Update and West Berkshire Local Involvement Network Royal Berkshire Hospital Dignity And Nutrition Study 2012**
FOR CONSIDERATION BY	Health Overview and Scrutiny Committee on 26 March 2013
WARD	None Specific

WOKINGHAM LINk

Report to the WBC Health and Overview Scrutiny Committee
26 March 2013

1. Activities

The last event arranged by the Wokingham LINk Steering Group was the Public Meeting arranged for 27 February 2013. The report of the meeting is included in the papers for this meeting. It was a positive meeting with a good rapport between speakers and the audience. We have received a good response from many of the audience. Ed Donald, Chief Executive of Royal Berkshire Hospital asked that the Wokingham LINk, as a last action, seek views of local residents on matters which were

a) well done at Royal Berkshire Hospital and;
b) those which were not.

The results gathered:-

a) Things done well at Royal Berkshire Hospital:
i) The Discharge Lounge is excellent and should be used as widely as possible;
ii) Recent Patient Conference was very good and the presentations were informative;
ii) The Arthritis Care meeting recently held at the Town Hall was of a high standard – that pattern should be followed by other outreach meetings.

b) Things not well done at Royal Berkshire Hospital:
i) Car parking and access to wheelchairs are both very difficult;
ii) Complaints and compliments procedures need further work;
iii) Pharmacy supplies contributions to the Discharge process still cause delays resulting in significant waits by patients. The Discharge Lounge can help significantly in this matter;
iv) Changes in timing of follow up appointments can be random and inexplicable. There are frequently delays which worry patients. This is still a major cause of concern.

If members of HOSC would wish to add their contributions the LINk would be pleased to add them as an anonymous basis either at the meeting or after.

2. The draft of the final Wokingham LINk Annual Report has been circulated with this report.

Residents whose contact details are recorded on the database have been offered the opportunity to have their details removed a small number have accepted (See page 12 of the Annual Report).

The Wokingham LINk Steering Group registered their support at their last meeting that the resulting list on the database is transferred to the Board of Healthwatch Wokingham Borough as it is hoped that it will contribute to a useful tool for that organisation.

3. **Projects which will be handed over to Healthwatch Wokingham Borough are:**

i) NHS Dentist Patient Information Project – the Report of Information gathered by the Wokingham LINk;
ii) Dignity in Care
a) Report on Dignity and Nutrition at the Royal Berkshire Hospital by Tony Lloyd when complete;
b) Report on Dignity and Care in Hunter Ward by Pat Evans and Michelle Wooff when complete.

4. Two reports of recent surveys on the Report on Dignity and Nutrition at the Royal Berkshire Hospital February 2013 and a Joint Survey on Incontinence February 2013 are attached to the report. They are produced by Tony Lloyd and he will speak to them now.

Report from the Wokingham LINk's Public Meeting

Wednesday 27th February 2013
Crescent Resource Centre, Earley

Guest speakers: Brian Harrigan, Compliance Manager, Care Quality Commission (CQC). Katie Summers, Operations Director, Wokingham Clinical Commissioning Group (CCG) and Ed Donald, Chief Executive, Royal Berkshire Hospital NHS Foundation Trust.
The Wokingham LINk held a Public Meeting to hear about some of the changes in how our health services are provided, how the quality of that care is monitored and the importance of patient feedback in shaping the way that care is provided.

Some of the content of the question and answer sessions are recorded at the bottom of this report.

21 members of the public attended.

Christine Holland, Chair of the LINk Steering Group, welcomed everyone to the meeting.

Talk by Brian Harrigan, Compliance Manager, Care Quality Commission (CQC)

Brian said his back ground has been in the police service and his fairly new job with the Care Quality Commission came about following a need for his family to look for services that could help with the needs of an older relative.

Talk covered

- The recent Francis Inquiry and the final report into the care provided by Mid Staffordshire NHS Foundation Trust. Following the recommendations from this report the CQC will be concentrating on 5 key areas to tighten up their role in regulating hospitals.

Presentation by Katie Summers, Operations Director, Wokingham Clinical Commissioning Group (CCG).

Stephen Madgwick, Lead GP for Wokingham CCG was also in attendance and introduced Katie. Katie said that her background in the NHS is in cardio thoracics nursing and she had moved into commissioning to have a greater impact on patient care.

Presentation covered

- Explaining what the CCG is: deciding which health services should be provided,

who will provide them and how they should be paid for, meeting needs of the population. The CCG has financial challenges and needs to balance priorities to ensure affective spending, most of which goes on secondary care.

- Services that the CCG commission
- The CCG Board (there are 2 lay members, one representing patient and public involvement and one for governance)
- How the CCG as an organisation is made up
- How the CCG will work with patients and the community: partnership funding (approx. £700,000 has been given to voluntary projects), working with Healthwatch and the Health and Wellbeing Board .
- Engaging with patients and the community - Debbie Milligan, Lead GP for patient and public engagement has already started work speaking to community groups. January figures showed that 1834 people had registered with a patient group through their GP surgery. A consultation on the Health and Wellbeing Strategy is about to start. Every meeting of the CCG will start with a patient experience and then go on to discuss how the CCG needs to meet the patients needs better in the future.
- Communications – the CCG website which goes live 11th March and will have a patient experience page that patients can engage with. Looking to developing a newsletter so that patients can be aware what the CCG is doing.
- At the end of April the CCG will be looking for patient and public input to their Commissioning plan and will want patients and the public to monitor this and provide feedback in the future.
- The Commissioning plan reflects the Joint Strategic Needs Assessment and links in with the Health and Wellbeing Strategy for Wokingham. This has 5 key themes: Promoting good health, Older people and long term conditions, Emotional health and wellbeing, building new communities, Reducing health inequality.

Talk by Ed Donald, Chief Executive of Royal Berkshire Hospital NHS Foundation Trust.

Ed said that his career has been in the health service for 25 years and that he chose to come to the Royal Berkshire Hospital because there is a strong feel of support by it's communities. Ed had spoken with Wokingham LINk participants early in his role at RBH and has addressed some of the things that people raised then: increased budget to help with patient transport, increase in outpatient follow up appointments. Hospital discharge was another concern raised at that time and the Trust have made changes but still needs improvements, this is still being worked on. Ed asks that if anyone has something to share around the service and care experienced at the hospital they let him know, it will be welcomed and it will be acted on.

Talk also included

- How he sees that the hospital can stop the Mid Staffordshire problems happening at RBH. It uses the Jarman Index looking at the survival rates and readmission rates
- Complaints – Ed personally signs off all complaints himself so he is aware of them.
- Monitoring wards - Ed will visit wards at night and weekends to see for himself what patient care is like and to see what works and where wards are not doing well. Wards hear of this and know that they could be visited without notice.
- NHS Choices rates RBH as being a 4 (out of 5) star service (an improvement

on the 3 star previously) the hospital is ambitious and wants to be 4½ then 5 star performer.

- Staff also feedback on patient care in a survey asking if they would recommend the hospital to family and friends, the rating has improved – after internal initiatives the hospital is now in the top 20% of hospitals nationally in the results for this survey.
- RBH is constantly looking at improving care and the patient experience.
- Stroke Services have been increased and are now available 24/7.

Question and Answer Panel Session

Q: A suggestion more than a question that one patient and public involvement telephone number be provided for all bodies (CQC and NHS) to make it easier for people to know where to go to give their feedback.

A: Healthwatch can be the main route through which everyone can provide their feedback. (This was countered by the suggestion that Healthwatch may not be seen as independent by everyone when it is funded by one particular body ie. The Local Authority).

Q: Ed was asked about care of vulnerable people.

A: There is a big awareness programme in RBH at the moment on dementia. (Additional comment that it is felt that services for Learning Disabled is lacking)

Q: The Learning Disability sector can you comment on the budget restrictions?

A: Stephen Madgwick responded that the more that can be done jointly between services the better. Age is a barrier for clients in a few areas not just learning disabilities. Berkshire Healthcare have a programme to look at how services can be joined up so that people receive a seemless service. GP's are hearing what the problems are and are working with Berkshire Healthcare to challenge these.

Q: Section 75 of the Health and Social Care Act relates to competition across the NHS and commissioning having to put services out to tender or go to Any Qualified Provider (AQP) what do you think will be the impact of this.

A: Stephen - The current flavour is to offer patients greater choice
Ed – RBH had a good audiology department but despite this RBH have had to put a lot of staff time into tendering to continue this service recently.

Q: Do you have a Whistleblowing policy and what nursing training is provided.

A: Ed – Yes we do have a Whistleblowing policy. We do have full induction training for nurses.

Q: Why isn't more notice given for CCG public meetings.

A: Katie – the 5th March is the first of the CCG board meetings and we will be shortly publishing dates for the next 12 months so that people have more notice to attend.

Discussion was held on Infection control.

Q: I can sit in hospital patient areas and look at posters on infection control and watch staff ignore the hand cleaning gels. Why is it not taken more seriously.

A: Ed – We do look at this internally and do random spot checks but I would ask that patients point out when this is happening and feedback when they see this. I would also be open to discussing how we can monitor this more closely perhaps through a mystery shopper scheme.

Q: Stephen asked if the meeting could answer why adults 40+ are using A&E so heavily.

A: One person suggested that one older person said that they had turned to emergency services when they had become confused about who they needed to call and did not

know what their GP contact details were.

Other items discussed included:

- Patients being in hospital that did not need to be there.
- Population getting older and people getting heavier is driving up the need for services.
- Electronic Patient Records.
- Relationship between Brants Bridge services and other East Berkshire hospitals needing to improve as patients are not being given the choice to go here for treatment.

* *

Some of the feedback after the event

I thought it was excellent to have the opportunity to find out about the changes and have those people round the table willing to be open and up front and available for questions. If there are more meetings like that I would like to bring my clients along. It's an invaluable opportunity for communication with the people who are able to make the decisions.
Marjie Walker, The Link Visiting Scheme.

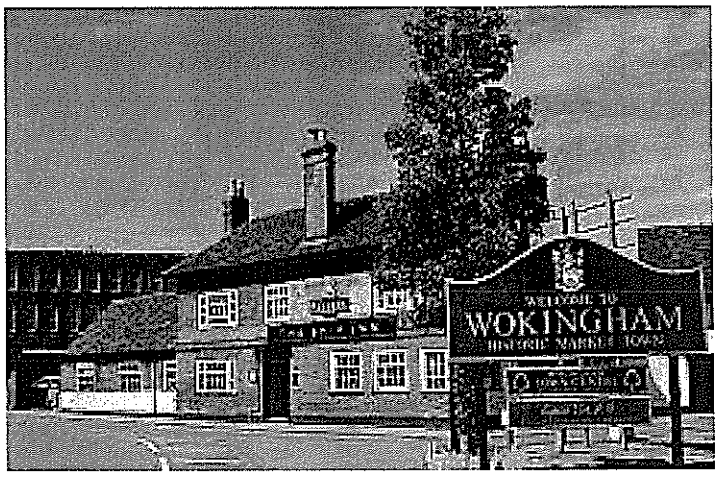
If you would like a copy of the presentations, or you have any feedback following the Public Meeting, please contact Michelle Wooff at the Wokingham LINk by the 28th March.

Wokingham LINk will no longer exist after 1st April.

tel: 0118 989 3959
mobile: 0791 8055 089
email: michelle.wooff@wokinghamlink.org
Website will still be available and carry the contact information for
Healthwatch Wokingham Borough

DRAFT
Annual Report for the Wokingham LINk
(Local Involvement Network)

1st April 2012
to
31st March 2013



Wokingham LINk

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Introduction from the LINk Chair, Christine Holland

As the Wokingham Local Involvement Network (Link) moves to its close on March 31st 2013, I find it is the people who most come to mind from the 7 years of the life of the LINk.

In 2007 the public were stated to be the source of the information which would guide the work of the LINK Steering Group and the initial guidance was that the initiation of an investigation should depend upon more than one person raising a matter and that "issues" should be the basis of reports. Thus the instructions given by the LINk Host and the Commissioners. However it soon became clear that the public were not keen on raising a matter unless it was serious and flagrant, affecting usually a relative or friend. Then the Complaints system was soon found to be the more salient means of dealing with these very important incidents and significant improvements were made in the Complaints process. Members of the LINk Steering Group soon found that rarely did the matters that were raised only affect an individual – so often when one person raised a matter - many heads were nodding in agreement and initiating action on a single report often quickly gathered additional supporting comments.

The average older person in the UK may suffer both indignity and lack of respect during care, but having recounted the often distressing events, they finish by saying "but you won't tell anyone will you" and since a very large proportion of both NHS Healthcare and Local Authority Social care patients are older, we believe that many matters are probably not raised so that action could be pursued. Once it was realised that waiting for issues would not be productive, two members of the Steering Group, Pat Evans and Michelle Wooff acted and attended meetings of Older Persons groups finding fertile ground for discussion which identified difficulties. This became a template for meeting the public as patients and discovering the matters that were causing concern. It is still true today that taking up the concerns of one person can uncover that it is not usually unique. It has taken years to establish the awareness and trust that produce reports of matters relating to present or future arrangements for care, but once again the changes to Healthwatch Wokingham Borough are likely to initially reduce the essential reports from the public. However younger generations show signs of much more readiness to speak up if they feel attitudes threaten their required care and use of modern communication such as twitter and facebook seems likely to give the public greater freedom of contact and comment.

I have referred to members of the Steering Group and there is a full list of those who have served on that Committee elsewhere in this report. However I would like to especially thank some members who have remained active since the inception of the LINk.

Pat Evans, Vice Chair of the LINk Steering Group and Leader of the Engagement Group which did much good work in going out to the public in situations which made the public feel comfortable and able to report on the experiences which caused them concern. She then followed up by reporting these matters to the appropriate person and reporting back any results achieved.

Michelle Wooff, Wokingham LINk Development Officer for much of the 7 years. She shared in the engagement activity and has in her own right established connections with many Wokingham User Led organisations and is for many the voice on the telephone when they ring the LINk office or which replies to their internet communication.

Tony Lloyd, Financial Officer of the Wokingham LINk, Chair of SELLNet (South East LINks Network) and Chair of the West Berkshire LINk. A gentlemen who works hard and has a phenomenal ability to gather and analyse the information produced at a bewildering rate by the many parts of the Department of Health. He has ensured that the Wokingham LINk was aware of this mass of information and also ensured that Wokingham LINk did not over spend and indeed made good use of its reduced circumstances.

Hugh Dempster came to Wokingham LINk from Berkshire Ambulance Service Forum.He became very interested in the physical welfare of NHS patients and did sterling work in ensuring ,through his work on the Community Care sub-committee of the Berks West PCT by continually raising issues like falls and other Serious Untoward Incidents eg pressure ulcers. This ensured that there was appropriate investigation and recommendations made so that lessons were learnt t. As a result of this committee the incidence of these has been reducing.

Wendy Teeton joined the Wokingham LINk from the Royal Berkshire Hospital PPI Forum and chose to represent the Wokingham LINk on the Royal Berkshire Hospital Patients Panels which replaced the Forums. Despite her physical difficulties she was an active member of the LINk Steering Group and her sensible view of matters often illuminated discussion. The Steering Group were saddened at her sudden death in June 2012

The third group of people encountered while working with the Wokingham LINk are the Providers and Commissioners of services. When the LINk succeeded the Patient Forums they were directed to monitor and report on the Social care provided in Wokingham Borough as well as the NHS Healthcare. Those members who had transferred from the Patient Forum had the advantage of having built relations with NHS Healthcare staff over the previous 5 years, and also found that the emphasis on the Patient and Public Involvement in the NHS led to easier establishment of LINk connections. These such as PALS and the PCT Network flourished and encouraged Patient and Public Involvement by individuals in Healthcare matters.

There are signs that some such connections are growing in the Local Authority areas of responsibility. I would like to thank the two Chairmen of the Wokingham Borough Council Health and Scrutiny Committees, Gerald Cockroft and Tim Holton, for their courteous and professional support. Also Mike Wooldridge who has over the years worked to ensure that the LINk was given the information needed for its work.

However the many re-organisations in the Wokingham Borough Council in recent 4years have made it difficult to build relationships and the current general re-organisations in the whole Health field reduces the possibility of building the useful and effective connections which would support ensuring good care for the residents of Wokingham Borough.

Christine Holland

The LINk Host – Support Horizons CIC (Community Interest Company and User Led Organisation)
Support Horizons has provided host arrangements of the LINk since 1st May 2011.

Support Horizons provide flexible and personalised support for people with personal budgets or direct payments and offer an Individual Service Fund where they will hold the personal budget on someone's behalf. They help people to select their staff, plan their support schedule and help come up with ideas of how to get the most from their budget.

The LINk Steering Group Members and co-opted members

Christine Holland	Pat Evans	Wendy Teeton
Hugh Dempster	Tony Lloyd	Kay Gilder
Jenny Butler	Norman Raybone	Kathy Smallwood
Bill Smallwood	Patricia McNally	

Names of authorised representatives (enter and view team)

Christine Holland	Pat Evans	Tony Lloyd
Hugh Dempster	Jenny Butler	

The LINk would like to thank everyone who has supported our work over the year including Nakhat Zahir and Paul Williams. The LINk would also like to thank all of our stakeholders and colleagues in the NHS and at Wokingham Borough Council.

Monitoring and scrutinising services

PEAT (Patient Environment Action Team) Inspection at Wokingham Hospital

PEAT Teams carryout assessments of all hospital and inpatient units with 10 or more beds assessing improvements to non-clinical assessments of care ie. Privacy and dignity, food and environment. PEAT teams consist of staff covering; clinical, catering, domestic services and include patients and their representatives and members of the public.

A member of the Wokingham LINk joined the PEAT team at Wokingham Hospital this year.

Project work in 2012

Review of Adult Social Care (joint project with Wokingham Borough Council)

In 2011, Wokingham Borough Council changed the way new and existing customers access social care services. Within the new adult social care pathway, the Council's traded company, Optalis, manages most of the non-statutory services previously provided by the Council. Statutory services are provided by the Council's adult social care service. In addition, social care customers and people who are not eligible for social care services can also access prevention services commissioned by Wokingham Borough Council and provided by external organisations and signposting services provided by Wokingham Direct (an in-house customer information service).

The customer experience of the transformed social care services was reviewed jointly by Wokingham Borough Council and the Wokingham LINk in May and June 2012. The review focused on the customer experience of different processes such as the assessment, reassessment, reviews, support planning as well as information, prevention and support services, safeguarding and the overall satisfaction with self-directed support.

Over 100 social care customers and carers gave their views during workshops, telephone interviews and by filling out questionnaires.

The final report made 28 recommendations for improving the social care pathway and in response to this Wokingham Borough Council have put in place an improvement programme to address the recommendations.

LINk Legacy (joint project with Wokingham Borough Council)

The Wokingham LINk Legacy Project was initiated in August 2012 to identify the learning, achievements and challenges encountered by the Wokingham LINk. The information contained in the report is aimed at helping with the commissioning of the local Healthwatch and ensure that this new organisation is able to draw on the lessons learned and use the established links and partnerships to effectively engage with the local community.

Data for this report was collated from various sources including reports, Wokingham LINk's website, minutes of meetings as well as face-to-face interviews with the LINk's participants, commissioners and representatives of organisations working in partnership with the LINk.

In addition, a survey designed jointly by Wokingham Borough Council and the LINk was distributed to a wide range of stakeholders . 200 copies of the questionnaire were sent out by post and around 500 electronically to LINk participants, the LINk Steering Group and a range of voluntary sector organisations as well as representatives of Wokingham Borough Council and NHS.

There were plenty of opportunities for stakeholders to give their views as part of the LINk Legacy Project as this was widely publicised via emails, LINk bulletins, presentations at voluntary sector and partnership boards meetings.

Review of Information for NHS Dental Patients – October 2012

NHS Berkshire, Dental Communications Group asked Reading and Slough LINks to carry out a review of information for patients held by NHS Dental Practices. The project was then extended to include Wokingham, Bracknell and West Berkshire LINks.

The project looked at the range of services offered by practices, the charges relating to those services and entitlement to receive certain services on the NHS. This involved members of the LINk enter and view team carrying out visits to 9 NHS dental practices in Wokingham to speak to staff and look for patient information and following this reviewing patient leaflets and practice websites.

NHS Berkshire believes that improved information to patients via leaflets, websites, and within the practices would help address theses issues, and improve the service patients are receiving from their NHS dental practice.

An interim report with recommendations and completed questionnaire's with LINk findings was sent to each of the practices visited and a final joint report with 'key themes' from each of the Berkshire LINks that took part in the project was sent to NHS Berkshire. The report is to be used to share best practice and improve the information provided for NHS dental patients and in March 2013 it was presented to the PCT's Commissioning Group.

Dignity and Respect Survey - Royal Berkshire Hospital Foundation Trust Patients

The LINk is supporting a survey questionnaire to gauge how patients feel they have been treated in a dignified and respectful way. The survey is being distributed by hospital staff to patients when they are discharged and can go home. 500 surveys have been made available and will cover 25 hospital wards. This project is being led by West Berkshire LINk and the final report was published in March 2013.

Two examples of poor patient experience at the Royal Berkshire Hospital Foundation Trust were reported to the Wokingham LINk in 2012.

In July an escort of a disabled patient attending the Pre-Operative Assessment Clinic (POAC) for Orthopaedic surgery reported her concern for disabled patients with painful limbs who have to:

- negotiate difficult access to the clinic
- mobilise with wheelchairs/walking aids in a small crowded waiting room
- mobilise between 4 treatment rooms to have tests performed
- mobilise to Orthopaedic Xray and then to Physio in North Block
- suffer a great deal of pain and exhaustion in a 4 hr process

A member of the Wokingham LINk reported poor experiences during a 6 day stay for planned surgery in September, with loss of privacy and dignity due to lack of staff courtesy and communication. They reported this to the Trust :

- The Admission – very fast processing, no time for questions or reassurance
- The Post-op ward – given no information, no one to ask what is happening next
- There were no introductions or offers of help made
- Screening only gave privacy from other patients, staff professionals visit as they please without checking that the patient is ready
- Pain relief options were very limited

Recommendations for better patient care were made:

1. Until Pre-Operative Assessment Clinic access is improved disabled patients are advised, before their appointment, about the mobilisation issues they will encounter on this site.
2. Information given to patients about the post operative period be improved.
3. For staff to agree with the patient what the treatment objectives are.
4. For all other professionals to be aware of patient's needs for privacy and dignity.
5. Informtion given to patients about clinical accessibility.
6. For the prioritisation of patient experience when the care package is contracted with the surgery commissioners.

The Chief Nurse of Royal Berkshire Hospital Foundation Trust dealt with these issues :

In the first example the Chief Nurse visited the Pre-Operative Assessment Clinic and agreed that the environment was 'less than ideal'. Actions were agreed with the Director of Planned Care Surgery to initiate a project to improve the pre assessment process and the environment. Two hospital patient panel members have been co-opted onto the working group.

In the second example a new initiative has been started that is Planned Patient Contact. It aims to have a nurse speak to each patient, checking the bedside and asking if the patient needs any help on a regular basis each day. A welcome letter is to be sent to all patients admitted to the ward explaining the ward management and

routines. Time to be set aside to talk to patients each week. Multi disciplinary team meetings to be held each week to help manage the care giving programme.

Relationship with our Local Authority

The LINk have continued to build relationships with the council and have supported awareness of local services and new initiatives for the community.

Westmead Stakeholders Group Wokingham Borough Council
The LINk continues to represent the people who use Westmead day services to ensure that their interests are always being considered. New premises in Woodley are being planned to include a shared services resource and will include rehabilitation services. The Westmead group are also looking at increasing access to hydrotherapy at Royal Berkshire Hospital Foundation Trust.

Health Overview and Scrutiny Committee (HOSC)
The LINk attends HOSC meetings and regularly reports on activities. The committee received a presentation on the joint LINk and Wokingham Borough Council report on the Review of Adult Social Care. A presentation which also included a Choice Champion who represented the social care customer.

Shadow Health and Wellbeing Board
A shadow health and wellbeing board has been established to improve health and wellbeing and reduce health inequalities for Wokingham Borough. The board includes members from both the local authority and each of its partner clinical commissioning groups and it will develop the Joint Strategic Needs Assessment (JSNA) and Joint Health and Wellbeing Strategy (JHWS) for Wokingham. The LINk Chair attends the Shadow Health and Wellbeing Board meetings to represent the community voice. A role which will be handed over to Healthwatch in April 2013 when the Health and Wellbeing Board will be formally established.

Local Account
The LINk has supported Wokingham Borough Council in preparation for a Local Account of Adult Social Care. This involved engagement exercises where people were given the opportunity to shape the Local Account and get involved in an editorial board in December.

Relationship with Wokingham Clinical Commissioning Group (CCG)

The LINk initiated an engagement exercise at the Indian Community Centre in Reading where a member of the CCG Board has addressed concerns around GP access. The LINk also initiated a meeting between the CCG and Wokingham Deaf Services Team where the CCG have listened to issues experienced by people who are deaf and deafblind and will be discussing this with the CCG Board. The CCG also advertised it's wish to engage with community groups through the LINk's final newsletter in 2013.

A member of the LINk represents the patient and public voice on the Clinical Commissioning Group Board for Wokingham, a role which will be taken over by a lay member once recruitment has been completed.

Relationships with local NHS Trusts

The LINk has continued its excellent relationship with local NHS Trusts and held regular meetings with them and our colleagues from all Berkshire LINks to share information and feedback.

NHS Trusts have continued to be open and transparent and have kept the LINk up to date with future plans and service changes. The LINk have helped support opportunities for involvement and contribution from patients and the public through promotions in their newsletters and bulletins.

Berkshire Healthcare NHS Foundation Trust

Since becoming responsible for providing community based health services in April 2011 in addition to mental health services for Berkshire the Trust have undergone some changes in staff but the LINk have maintained a strong relationship.

Patient and Public Involvement

Liz Daly joined the trust as Head of Service Engagement & Experience and subsequent patient experience reports improved to make sure the learning from customer complaints is captured. Jo Gilbert has continued to support the LINk in keeping us informed on the Shaping the Future consultation and changes in services and responding to our requests.
The LINk have commented on the questions for a patient survey which is being rolled out with the use of an electronic patient feedback device.

The LINk are disappointed that there will be no patient involvement in Clinicial Governance within the Trust.

Royal Berkshire NHS Foundation Trust (RBHFT)

Patient and Public Involvement work

A member of the LINk attended the Trust's Patient Partnership Standing Conference in November where excellent presentations were given by staff on patient care and included projects planned to improve care.

The LINk has continued representation on behalf of patients and the public with the following: **Medical Panel** (developments in the medical division of the Trust), **Dementia Steering Group** (a multi-disciplinary panel covering all aspects of the care of patients at

the RBH who also have dementia or delirium) and **Cross Panel Dementia Group** (Members pursue issues associated with dementia support ie. nurse and care worker training, literature for relatives and carers and "Memories" books. The LINk also have representation with the **Clinical Governance Committee** (The Trust's main group monitoring the provision and quality of clinical governance).

Primary Care Trust

Patient and Public Involvement

Cath Price of the PPE Team has continued to support the LINk in keeping us informed about public engagement activity. The LINk have been invited to be involved in a 111 sub group looking at engagement and awareness of this new service as it is rolled out in our region.

Speakers from the Trust have attended LINk meetings to provide updates on changes in the NHS and the move to Clinical Commissioning Groups.

The Chair of the PCT GP Commissioning Group has thanked Paul Williams (on behalf of the LINk) for his very valuable input into the work of the group. Paul will continue with his work as a patient's representative of a Berkshire diabetes group in the future.

Patient Experience Reports are provided by the Trust and the LINk are made aware of these.

Patient and Public representation from the LINk

The LINk has representation on;

- Berkshire Pharmacy Commissioning Group
- PCT Cluster Quality & Risk committee monitoring quality of commissioned services.
- Berkshire Wide Pharmacy Commissioning Group
- Clostridium Difficile Berkshire Zero Tolerance Symposium – Feb 2012
- Vascular Surgery Implementation Group (Berks, Bucks, Oxon)
- Berkshire Dental Commisioning Group
- Berkshire Dental Communications Group
- RBH Clinical Commissioning Group
- Berkshire Pharmacy Commissioning Group (BPCG)
- Berkshire West PCT GP Commissioning Group
- Day Opportunities Steering Group

LINk Event – Changes in Health and Social Care and How They May Affect You

This event in May 2012 included talks on the Health and Social Care Act 2012 that was

passed in March 2011, Putting People First and personalisation, personal budgets and prevention services, Next Generation Care and mental health services and Tomorrow's Community Health.

LINk at Local events

The LINk has supported local events whilst also promoting it's role. We have have also had a presence at local partnerships including; Wokingham Learning Disability Partnership Board, Wokingham Adult Safeguarding Forum, Wokingham Children's Safeguarding Board and Wokingham's Action 4 Autism Partnership.

The LINk Legacy and our handover to Healthwatch Wokingham

Healthwatch Wokingham

From the 1st of April 2013 Local Healthwatch will be in place to build on the work of LINk and become the local consumer champion for patients, service users and the public. It will take on the role and activities of the LINk and will have additional responsibilities ie. signposting and advocacy services. Healthwatch England will provide leadership and support to Local Healthwatch organisations.

Healthwatch will have a representative who will be a voting member on the Health and Wellbeing Board for Wokingham Borough.

LINk Legacy

Whilst the LINk have been able to address some of the lessons learned from the LINk Legacy project there are actions that can be taken forward to ensure a stronger Healthwatch for the future. The final report is to be ready in January 2013.

Dignity in Care

A Dignity in Care Board is to be set up for Wokingham Borough in relation to care provided within health and social care settings. Wokingham Borough Council has asked the LINk to be involved and to support this project Board. This new board will be supported through grant funding and the role to development this is being recruited to. There is an opportunity for the Healthwatch Enter & View role to be promoted as a resource to the Board once it is established.

Adult Social Care

Following the joint Review of Adult Social Care Report that the LINk and Wokingham Borough Council produced an action plan has been drawn up to address the recommendations. The LINk and Healthwatch should follow the progress of this plan.

The LINk year in figures

The number of LINk participants has continued to fluctuate this year as people opt out as they move jobs or out of the area. The LINk will ask all of it's participants to notify us where they do not want their details passed over to Healthwatch Wokingham Borough. The LINk has a total of 866 people registered to hear about it's work and the opportunity to get involved.

The LINk has had 11 active members on it's **Steering Group** who have been involved in decision making and supported the progress of project work.

The **LINk Enter and View Team** have 5 trained members who all hold a CRB (Criminal Record Bureau) check certificate (see page 12). The LINk has one further volunteer, Jane Lord, who has undertaken training to support this work.

Community participation in the work of the LINk

Informed Participants: are groups or individuals who register their interest in the LINk and receive information updates on the general work of the LINk as well as events and updates from the community.

Occasional Participants: are informed participants (individuals or groups) who also respond to a particular LINk issue, or attend a workshop or meeting on a specific topic. For example, someone who became involved in a one of our projects and had no further involvement with the LINk on any other work streams and requested to revert back to receiving the newsletter only.

Active Participants: are groups or individuals who have a high level of participation (i.e. someone who takes part in activity at least once a month), for example becoming involved in the steering group or sub group activities, or representing the LINk externally.

Number of LINk participants/members on 31/03/2011

Level of participation	Total	Of which:		
		People with a social care interest	Individual participants (including NHS and Local Authority Staff)	Interest group participants
Informed participants	868		632	236
Occasional participants	100		80	20
Active participants	20		17	3

Summary of Activity

Requests for Information in 2010-11

How many requests for information were made by your LINk?	43
Of these, how many of the requests for information were answered within 20 working days?	42
How many related to social care?	0
Enter and View in 2010-11	
How many enter and view visits did your LINk make?	0
Reports and Recommendations in 2010-11	
How many reports and/or recommendations were made by your LINk to commissioners of health and adult social care services?	3
How many of these reports and/or recommendations have been acknowledged in the required timescale?	3
Of the reports and/or recommendations acknowledged, how many have led, or are leading/contributed to, service review?	3
Of the reports and/or recommendations that led to service review, how many have led to service change?	1
How many reports/recommendations related to health services?	2
How many reports/recommendations related to social care?	1
Referrals to OSCs in 2010-11	
How many referrals were made by your LINk to an Overview & Scrutiny Committee (OSC)?	0

Our Finances

The LINk discretionary budget was further reduced in this financial year.

These figures are not audited by the LINk and are entirely based upon information received from the Council and the Host organisation.

Wokingham Borough Council LINk Funding 2012

	Hosts	LINk	Total
Expenditure in the year	28922	2282	31204
Accrual bfd		-540	-540
Net Expenditure in the 9m to Dec	28922	1742	30664

Wokingham Borough Council Grant allocation

		£	
Funds from Central Government		65625	
Expenditure in the year		30664	46.7%
Surplus retained by Wokingham Borough Council (inc contract administration)		34961	

Cumulative Position						
	2008/09	2009/10	2010/11	2011/12	2012(9m)	Total
Funding from Dept of Health	87000	87550	87697	87697	65625	415569
allocated as follows						
Wokingham BC Admin	5000	5000	5000			15000
Envolve	25000					25000
HAC	38640	72398	68038	1378		180454
Support Horizons				19285	28922	48207
LINk	1596	10030	8206	2470	2282	24584
accruals cfd	13358			540		13898
accruals bfd		-13358			-540	-13898
	83594	74070	81244	23673	30664	293245
Surrendered to Wokingham BC	3406	13480	6453	64024	34961	122324

Activities of a LINk member

The Essence of Care is Communication

The key feature of the LINk is monitoring the performance of Health and Social Services.

The purpose of this is to communicate the outcome of services used in terms of peoples personal experiences to the providers of services and recommend improvements that can help those indisposed by health or social problems to manage their daily living.

It is never easy to ask for help.

This is why the LINk visits and talks to groups of people in the community, some with special needs such as disablement from loss of mobility, sight and hearing, and listens to their accounts of experiences resulting from poor communication about the care they have received. The message that LINk aims to give is that the LINk is able to feed back these experiences to Providers as a system failure rather than a complaint which individuals do not want to make, with the expectation that recommendations for improvement will be implemented.

In September 2012, the Patients Association found that 80% of people surveyed wanted to be more involved in their care -- to talk to care givers about what is planned for them, to share decision making, and for progress and evaluation to be communicated to them. Frequently, clinical and nursing activities are task oriented rather than patient centred, in order to facilitate cost effectiveness, but do not allow time for the important communication of support and reassurance. This of course should be a spontaneous 'given' by a professional carer, in the knowledge that it can contribute towards the restoration of holism for a person parted from their normal daily life.

Recognition by Government of health and social needs to be met simultaneously does reflect a move towards the achievement of more holistic care to be available, in that the Providers of each have been working more in Partnerships with the possibility of one whole authority in the future.

Meanwhile, the work of the Wokingham LINk continues to focus on communicating with the public and patients, the providers, voluntary workers and all the authorities that contribute to the regulation of those involved in the provision of care.

Pat Evans - October 2012

Appendix 2

The end of some patient and public involvement roles

There are three areas of work that have interested me in my work as part of the LINKs Steering Group.
These are

(1) Committee work with South Central Ambulance Service (SCAS) as part of their Health and Safety Committee and on the sub-committee to investigate and consider Serious Untoward Incidents (incidents that are investigated to enable lessons to be learned). My role with SCAS ended as any Patient and Public Representation work was taken over by SCAS Governors.

(2) Committee work with Berkshire West PCT serving on the Governance sub - committee that dealt with Health and Safety associated with Community Care. This dealt with all Health & Safety affairs and Serious Untoward Incidents in the Community Hospitals and the Community at large.

    Since all this activity has been transferred to Berkshire Healthcare Foundation Trust there has been no public representation on this Committee in the same way. Hence again my Patient Representation work was ended.

(3) PEAT inspections in the Community Hospitals and having done one in 2012 which I felt was not organised well I have decided not to continue volunteering for these.

This has been a disappointing end to my time as a volunteer firstly as a Forum member with Royal Berkshire Ambulance Service then as a member of LINKs and on the Steering group and part of the SCAS public representation. I am not convinced as new arrangements have been made there is appropriate public representation to keep these sort of committees focused on patient care.

Hugh Dempster - December 2012

Contact details for Healthwatch Wokingham Borough from 1st April 2013

Nicola Strudley

Regional Manager, Help and Care

Telephone: 07920 506 401

Email: nicola.strudley@makesachange.org.uk

John Ferguson

Wokingham District Citizens Advice Bureau

First Floor, 26-28 Market Place, Wokingham, West Berkshire

Telephone: 0844 499 4126

Support Horizons

Support Horizons is the Host Organisation for the Wokingham LINk

West Berkshire LINk and West Berkshire Neurological Alliance

Joint Survey on Incontinence – Feb 2013

Contacts

Tony Lloyd - Chair West Berkshire LINk
tonylloyd25@googlemail.com

Man Liu Clarke – LINk support officer
Broadway House
4-8 The Broadway
Northbrook Street
Newbury
RG14 1BA

Tel 01635 760425
linksadmin@wbiln.com

John Holt
West Berkshire Neurological Alliance
johnmholtbsc@aol.com

Executive Summary

Background

Following a successful focus group conducted by the West Berkshire Neurological Alliance (WBNA) at Padworth in March 2012 (see Appendix 1) the LINk offered to facilitate a wider community survey of services for people with incontinence across the Western part of Berkshire.

Methodology

A draft questionnaire was developed by the WBNA in March 2012 and was sent out to member organisations and other stakeholders for comment.

After making some amendments a final version (see Appendix 2) was approved and 200 sets of questionnaires complete with reply paid return envelopes were prepared. We expected that it would be difficult to recruit people to the survey despite guaranteeing anonymity and so it turned out. We did manage to distribute all 200 through a variety of conduits including :-

WBNA member organisations
The West Berkshire incontinence service – Teresa Dunbar
17 other local voluntary organisations with an implied interest

The returned questionnaires were analysed and recorded by the LINk administration officer, Man Liu Clarke, on Excel spreadsheets.

The report was prepared by Tony Lloyd, the West Berkshire LINk chair, with advice from the WBNA and others.

A draft copy of the report was sent to the West Berkshire Incontinence service and an extract of their response is included in Appendices 5 and 6

Results

Out of 200 questionnaires distributed only 27 (14%) were returned. This was a **very** disappointing response rate.

Most of the statistics that follow are based on low numbers, so the findings should be regarded as indicating trends, flagging up possible concerns and indicating where priorities might lie for further data gathering.

Findings

1) There is a wide variety of experience of incontinence services and products .

2) A significant proportion of patients and their carers were having problems in coping with incontinence.

3) The continence adviser and the continence clinic are highly regarded for their understanding of the condition and for the help that they provide. This is in stark contract to GPs and consultants who are not generally so highly rated.

4) Many patients with incontinence are unaware of the incontinence service.

5) Those that do access the NHS incontinence service give it good ratings and there are few criticisms of NHS continence products apart from single examples of excessive bureaucracy and availability.

6) The voluntary sector was not rated highly for the support provided to patients with incontinence problems.

Recommendations

1) The commissioning of incontinence should be investigated further and reviewed leading to actions that will:

   a) improve the availability and quality of information about incontinence and what can be done for those in need

   b) improve continence training / knowledge of GPs and community nurses

   c) improve and standardise the continence care pathway leading to increased referrals to local specialist Continence Advisory Services

   d) reduce the misery of many local people living with incontinence

2) There is a clear need for GPs and consultants to recognise that many patients do not feel that they understand their incontinence problems or provide adequate help in dealing with them. It is recommended that they recognise these shortcomings and try to remedy them.

3) It is recommended that referrals to the incontinence service for a comprehensive incontinence assessment should be encouraged as should specific incontinence training for front line staff at surgeries.

4) CCG commissioners should ensure that there is adequate capacity in the continence services and review referral rates to identify anomalies.

5) Though not specifically derived from this survey but rather from the focus group (Appendix 1 – recommendation 6), it is recommended that the policy on the

provision of free continence care products to those in need should be made available in the public domain and should be reviewed as to content, appropriateness, relationships between quality and clinical value, consistency of current compliance and possible improvement..

6) It is recommended that relevant voluntary groups should bear in mind their low ratings for understanding and helpfulness and work with professionals to try to identify potential improvements.

Tony Lloyd (West Berkshire LINk)

John Holt (West Berkshire Neurological Alliance)

Feb 2013

Notes

The West Berkshire LINk is an independent Local Involvement Network. We have a statutory duty to gather the views of patients and the public about the health and social care services that they experience and to report those to commissioners and providers of those services. We are also required to make recommendations for the improvement of those services.

LINk Contact Details

Man Liu Clarke LINk administrator

Broadway House,
4-8 The Broadway
Northbrook Street, Newbury
RG14 1BA

Phone 01635 760425 e-mail linksadmin@wbiln.com

Tony Lloyd LINk chair e-mail tonylloyd25@googlemail.com

WBNA Contact Details

John Holt,
2, Clayhill Crescent, Newbury, RG14 2NP

Phone 01635 33582 e-mail johnmholtbsc@aol.com Web www.wbna.org.uk

Detailed Report

Demographics

The responses came from across the West of Berkshire [Reading 7, Wokingham 7, West Berkshire 10. 3 responses did not state the local authority area]

Two thirds of the respondents were women (17 out of 27) and there was a wide age range though 16 of the 26 who responded were older than 65.

A third of respondents (7 of 23) had no mobility impairment, another third (7 out of 23) used a walking aid and another third (9 out of 23) were wheelchair users.

12 of the 27 filled in the form themselves but the majority were completed by someone else, usually the spouse.

Type of incontinence

We asked people about the nature of their incontinence and received the following response.

	Not at all	Sometimes	Quite a lot	Most or all of the time
How bladder incontinence affects you?	12%	19%	19%	50%
How bowel incontinence affects you?	25%	25%	17%	33%

Likely cause of incontinence

81 % (21 of 26) advised us that their incontinence derived from a specific condition (Stroke, Parkinson's, dementia etc.) (See Appendix 3 for details) There was only one respondent who attributed it to child birth and this aspect of incontinence needs further investigation. (see Appendix 4 re Stress Urinary Incontinence and developments at the Royal Berkshire Hospital.)

How well people are coping with incontinence.

We asked how well people were coping with their incontinence and, out of 26,

- 7 (27%) said "not at all",
- 4 (15%) said "a little" ,
- 7 (27%) said "some of the time well" and
- 8 (31%) said "almost all of the time"

11 out of the 26 (42%) were therefore having regular or significant problems in coping with 69% coping only some of the time, a little or not at all

Help and advice

We asked people "Do you believe you have all the information, help and advice you need to manage your incontinence as well as you ever could?"

It was evident from the answers that a few people had been pleased with the help that they had received

- *Very good help from district nurse*
- *The help has been very good*
- *Yes, information / advice is good*
- *Because I employ my own PAs directly via LA DP&ILF, I have control over my bowel and bladder management that would not be possible via nurses.*
- *I am happy with the advice, help and products I receive to help me with my incontinence, and keep it under control and manageable.*

Others were more critical

- *As my husband's carer, I have to do all the managing. I have had to seek out information, help and advice. Nothing was suggested to me. Everything was a case of trial and error.*
- *Mainly night time incontinence. It has been very difficult to find advice and help - social services are not able to help, district nurse has given only limited help.*
- *No. There is quite a lot of help for bladder incontinence but the only advice for bowel incontinence is to eat more fibre and improve the diet. I don't know when I need to go or if I have been.*
- *I have had this problem since birth (there was a weakness on both sides of the family) and have attended various hospitals since the age of about 5 including. The Bladder Hospitals in London (4 near The Strand) and wish they could be more widely advertised even some doctors don't know of them.*
- *I found out about such things as waterproof mattress and waterproof duvet covers on the net. Leaflets explaining all these type of products should be available.*
- *Would like help with knowledge, ideas for dealing with dementia and incontinence. I am struggling. The products have to be bought are expensive, bed pads, washable slippers, carpet cleaning materials, bath aids that allow*

for appropriate washing.

- *My wife followed up articles/magazine ads anything that might improve my life. Professionals tend to only answer/deal with issues you raise instead of if this happens what we could do. You need to know the questions to ask in order to get an answer. If we ask too many questions it gets expensive as items cost money.*

- *Colon and Colitis specialist nurses and consultants be informed of the work of the NHS Colitis service and they, in turn, inform those diagnosed with Colon's / Colitis. If I had known that pads were available for night time use then both myself and my wife would have slept a little better during my last several flare-up. I still don't know if I am entitled to them or from where I get them.*

It is clear that a number of people face or have faced significant problems in getting adequate information about the condition.

Impact of incontinence

We asked people about the impact that incontinence had on their lives and received the following responses :-

	Very negative	Negative	No impact	Positive	Very positive
General physical health	4 (19%)	4 (19%)	13(62%)	0	0
Condition of my skin	3 (13%)	6 (26%)	12 (52%)	2 (9%)	0
Bladder infections	2 (10%)	7 (33%)	8 (38%)	3 (14%	1 (5%)
My psychological outlook	1 (4%)	9 (38%)	9 (38%)	4 (17%)	1 (4%)
Leading an active life	3 (12%)	7 (28%)	8 (32%)	6 (24%)	1 (4%)
My quality of life	2 (8%)	10 (42%)	8 (33%)	3 (13%)	1 (4%)
Personal relationships	1 (5%)	7 (32%)	13 (59%)	0	1 (5%)
My self-esteem	1 (4%)	10 (43%)	8 (35%)	2 (9%)	2 (9%)
Being fulfilled	1 (5%)	6 (29%)	12 (57%)	1 (5%)	1 (5%)

The main points from this table are

a) **The adverse impact on the individual's health** with 38% indicating an adverse affect on general health, 39% indicating an adverse affect on their shin condition and 43% reporting a negative impact on bladder infections.

b) **The adverse affect on peoples mental health** with 42% reporting adverse psychological impacts, 37% reporting an adverse impact on personal relationships and 47% reporting lowered self esteem.

c) **The adverse affect on peoples quality of life** with 40% reporting an adverse impact on their ability to lead an active life, 50% reporting a negative impact on their quality of life and 34% not feeling that they are fulfilled.

Needs

We asked people how easy it was to find things that they might need and they responded as follows :-

	Easy	Fairly easy	Not very easy	Difficult
Timely and suitable information	4 (15%)	11 (42%)	7 (27%)	4 (15%)
Timely and suitable advice	4 (15%)	11 (42%)	6 (23%)	5 (19%)
Effective management options	3 (12%)	8 (32%)	9 (36%)	5 (20%)
Effective products that suit me	4 (15%)	14 (52%)	3 (11%)	6 (22%)
Effective support	6 (23%)	11 (42%)	4 (15%)	5 (19%)
Ways to adapt to change	3 (12%)	8 (32%)	7 (28%)	7 (28%)

The table once again indicates a wide variation in experience and perhaps the most striking result is that more than half of the respondents think that it s not easy to find effective management options.

A typical comment is :-

Mostly incontinence information etc has come from trial and error solutions building up my experience of how to deal with situations as when and after they arise. Was given no information on aids to deal with results of incontinence from NHS sources.

Unsurprisingly, with management options not initially easy too to find, 56% reported difficulties adapting to change. The responses would seem to indicate that people affected by incontinence are likely to experience change and may have ongoing needs to be in touch with up to date advice.

Quality of Services

We then asked for people's views on the services available for incontinence by asking whether they agreed with certain statements. They replied as follows:-

	Strongly Agree	Agree	No view	Disagree	Strongly disagree	Not applicable
The NHS continence service is easy to contact	6 (24%)	8 (32%)	3 (12%)	5 (20%)	2 (8%)	1 (4%)
The NHS continence service is well run	5 (20%)	8 (32%)	7 (28%)	1 (4%)	1 (4%)	3 (12%)
The NHS continence service is well resourced	3 (12%)	5 (20%)	10 (40%)	4 (16%)	1 (4%)	2 (8%)
I get all my continence care products from the NHS	7 (27%)	7 (27%)	2 (8%)	2 (8%)	7 (27%)	1 (4%)
The NHS products I use are the right quality for me	3 (12%)	15 (58%)	2 (8%)	1 (4%)	1 (4%)	4 (15%)
It is easy to order or reorder continence care products from the NHS	6 (23%)	10 (38%)	4 (15%)	1 (4%)	2 (8%)	3 (12%)
I have enough space to store my continence care products	3 (12%)	12 (48%)	4 (16%)	4 (16%)	0	2 (8%)
I am given appropriate continence care prevention information from the NHS	2 (8%)	9 (38%)	5 (21%)	3 (13%)	4 (17%)	1 (4%)

This table indicates that clients generally regard the continence service as being well run (only 2 of 25 disagreed) though 7 out of 25 thought that it was difficult to contact and 5 out of 25 thought it was not well resourced.

Some respondents were not even aware of the NHS continence service

- *I didn't know that the NHS continence service existed until I was contacted by a third body about taking part in this survey.*

- *I have never tried to contact NHS Continence Service. Maybe I should.*
- *What care products are available from NHS?*
- *Was not aware of the NHS continence service*

There was a criticism about the bureaucracy

- *It now takes 2 weeks receive products as an application has to be made by provider for a prescription. The prescription returned before dispatch.*

and another about the NHS products

- *The products the NHS supplies are impossible to use. I am disabled and simply can't hold the pad in the net because I need one hand to hold on to something.*

And yet another about the availability of some continence products

- *I get the pads - 2 types supplied which is greatly appreciated but getting waterproof pants is very difficult. Boots are the only firm who keep them in stock. Various chemists can order them from a catalogue but they are very much more expensive and it isn't always very clear what they are like. The same applies to ones available on the internet. Most chemists and supermarkets now keep the pants with a pad as part of the garment but those are much more heavy to wear, not so discrete and not so easy to change if your need to when out shopping etc. I always carry a spare pad with me in case I need it and can go into a public toilet and change it and be dry and comfortable in a few minutes.*

- *I would like more advice as to where to obtain a neen / pericalm device.*

There is clearly some dissatisfaction regarding the need to pay for continence products and this raises questions about the assessment process that is currently adopted.

The products themselves seem to be satisfactory (only 2 of 26 disagree) and relatively easy to reorder (3 out of 26 disagree) and store (4 out of 25 disagree)

Only 11 out of 24 felt that they had been given appropriate information on prevention and this is a cause for concern

Understanding and helpfulness

We went on to ask about the extent to which healthcare professionals understood peoples incontinence needs and were helpful.

The responses are set out below

	Not applicable	Not at all	Small Extent	Quite well	Very well
GP	4 (17%)	4 (17%)	7 (29%)	4 (17%)	5 (21%)
District/Community nurses	7 (29%)	2 (8%)	4 (17%)	4 (17%)	7 (29%)
Continence advisor	7 (32%)	3 (14%)	0	1 (5%)	11 (50%)
Specialist Continence clinic	11 (46%)	3 (13%)	0	3 (13%)	7 (29%)
Urology or bladder specialist	13 (57%)	4 (17%)	2 (9%)	3 (13%)	1 (4%)
Other hospital staff	11 (46%)	5 (21%)	2 (8%)	5 (21%)	1 (4%)
Physiotherapist	15 (65%)	4 (17%)	0	3 (13%)	1 (4%)
Psychological support worker	15 (65%)	4 (17%)	2 (9%)	2 (9%)	0
Occupational Therapist	16 (70%)	4 (17%)	1 (4%)	2 (9%)	0
Social Services Care Manager	14 (61%)	5 (22%)	1 (4%)	3 (13%)	0
Voluntary sector	14 (61%)	3 (13%)	4 (17%)	2 (9%)	0

It is difficult to interpret this table due to the number of "Not applicable" responses. The table below restates the data by excluding those responding 'not applicable'

	Number Rated	Not at all	Small Extent	Quite well	Very well
GP	20	4 (20%)	7 (35%)	4 (20%)	5 (25%)
District/Community nurses	17	2 (28%)	4 (23%)	4 (23%)	7 (41%)
Continence advisor	15	3 (20%)	0	1 (7%)	11 (73%)
Specialist Continence clinic	13	3 (23%)	0	3 (23%)	7 (54%)
Urology or bladder specialist	10	4 (40%)	2 (20%)	3 (30%)	1 (10%)
Other hospital staff	13	5 (38%)	2 (15%)	5 (38%)	1 (8%)
Physiotherapist	8	4 (50%)	0	3 (37%)	1 (12%)
Psychological support worker	8	4 (50%)	2 (25%)	2 (25%)	0

Occupational Therapist	7	4 (57%)	1 (14%)	2 (28%)	0
Social Services Care Manager	9	5 (55%)	1 (11%)	3 (33%)	0
Voluntary sector	9	3 (33%)	4 (44%)	2 (22%)	0

Perhaps the most striking line in these tables is the comparatively poor rating of GPs and district nurses in comparison with the continence adviser and the specialist continence clinic though the fact that a significant proportion of respondents chose the "not applicable" option may mean that they were never given specialist advice. Even more of a concern is the fact that the urology or bladder specialists were not thought to be particularly helpful even compared to other hospital staff.

It is disappointing that the voluntary sector fared so badly and the reasons for this need to be better understood. Is it that people are reluctant to seek help or that they regard it as a topic for professionals?

The bulk of comments are from people who are not receiving and in some cases have never received help or advice about incontinence.

- *The only people involved in my care are doctors, district nurses, family and paid carers. I have never been referred to a specialist although I have had bowel incontinence for 18 months and I first approached my GP for help in February 2011.*

- *We are completely on our own. There is no follow up whatsoever. I had to sort out day time pads with help of local chemist. I became very depressed while dealing with my husband's incontinence in 2010. I needed a lot of support then I got none.*

- *Have not had a check up appointment for at least five years.*

- *Other than* providing *access to NHS pads and a wheelchair with bedpan (which I do not use) there has been no help at all.*

- *Apart from the 'Urology' I have answered 'not applicable' as I have never been contacted by these people and didn't know that I could contact them.*

- *The only person who has given any help has been the district nurse, she is limited to offering only 1 kind of pad.*

- *Once it was discussed, I had more than £23,000 in the bank, I was left to help myself. This meant all health care was left to my husband (who is a retired accountant not medically trained)*

There was one complimentary remark

- *Nurse Jo Balls has been very helpful at Wokingham Hospital*

Conclusions

1) There is a wide variety of experience of incontinence services and products by patients.

2) A significant proportion of patients and their carers were having significant problems in coping with the condition.

3) The continence adviser and the continence clinic are highly regarded for their understanding of the condition and for the help that they provide. This is in stark contract to GPs and consultants who are not generally so highly rated. There is a clear need for GPs and consultants to recognise these shortcomings and try to remedy them.

4) Many patients with incontinence problems are unaware of the incontinence service. It is highly rated and effective. CCG commissioners should ensure that there is adequate capacity and that GPs make more referrals to the specialist service

5) Those that do access the NHS incontinence service give it good ratings and there are few criticisms of NHS continence products apart from single examples of excessive bureaucracy and availability.

6) The quality and availability of information about products and services for people with incontinence requires improvement.

7) Incontinence should be adopted as a specific subject to commission some further local investigations leading to actions that will:

   a) improve the availability and quality of information about incontinence and what can be done for those in need

   b) improve the training and knowledge of GPs and community nurses in continence matters

   c) improve and standardise the continence care pathway leading to increased referrals to local specialist Continence Advisory Services

   d) improve the performance and perceived approval ratings of urology consultants and general hospital staff

   e) reduce the misery of a significant proportion of local people living with incontinence

8) The voluntary sector were not rated highly for the support provided to patients with incontinence problems. Relevant groups should bear this in mind and work with professionals to try to identify potential improvements

Appendix 1

Report for Berkshire West Neuro Local Implementation Team

`Living with incontinence'

Findings from a focus group held at Padworth on 26th March

2012 Executive Summary

Poor control of continence can have a major impact on quality of life, psychological and physical health, personal relationships and self-esteem. Attendees generally had found ways of coping with the challenges of urinary and faecal incontinence, while generally experiencing difficulties in finding timely and suitable information, advice, products and support. The quality of advice from health professionals is variable, sometimes overlooking individual needs. Service delivery could be better coordinated and is inadequately resourced or inappropriately deployed, or both. A service review and upgrade is recommended.

Limitations of this consultation

Neurology conditions are many and diverse and this consultation covered only a limited cross section, with only 9 attendees representing 4 conditions, (one by proxy) a bias as regards age range, (all in the age range 30-70 yrs, noting that the epilepsy incontinence experience started at school age) and a feminine bias, (2M, 7F). There were two carers present. No participants were wheelchair-bound, although one carer looked after a wheelchair-bound doubly incontinent wife and some participants had used wheelchairs previously. Three attendees used walking aids. There was one family support worker present. All attendees were in communication with several others experiencing incontinence. Delegates lived in various locations across Wokingham, Reading and West Berkshire.

Neurological Alliance volunteers led the discussion and two independent sets of notes were taken of the proceedings, (both appended). Care was taken to avoid use of leading questions and attendees determined most of the direction of most of the meeting. There were no service providers, commissioners or statutory sector personnel present. The purpose of the meeting was circulated in advance and attendees were asked to prepare, which all had done. No individual affected by a very rare condition was present, noting that the underlying diagnosis that may have been the primary cause of incontinence was frequently referred to as having some significance as to information needs and management options.

Either individually or collectively, those taking part should not be thought of as being `representative' or `typical'. They showed considerably above average personal courage by volunteering to take part and to speak about very intimate matters that most people would find embarrassing to discuss, also displaying high levels of respect towards each other and all commitment to improving services for others.

Analysis of those present:

2 representatives with Parkinson's Disease 2
representatives with Multiple Sclerosis 1
representative with Post Polio syndrome 1 carer
of a person with Post polio syndrome
1 carer of a person with MS
2 independent voluntary sector recorders
7 of the 9 attendees were female.
1 person acted as proxy for a young man with epilepsy since childhood.
There were no service managers, commissioners or statutory sector observers

The pre-advised agenda

1. Welcome and introductions
2. Purpose and focus group `rules'
3. *Open discussion on experiences about:*
    - obtaining information and advice about incontinence
    - obtaining suitable products and services
    - leading an active and fulfilled life
    - managing when things go wrong
    - adapting to change
    - costs of incontinence
    - what makes a good continence advisory service?
4. Recommendations for the statutory, private and voluntary sectors

The group determined its own priorities for discussion within the above framework.

Themes that emerged

1. Embarrassment barriers surrounding incontinence.

2. Information about incontinence is not readily available.

3. The underlying neurological condition (or other specific diagnosis) is often relevant to determining the best management options. Condition-specific advice exists but is not readily available. Some advice lacks a patient-centred approach.

4. Incontinence affects psychological outlook, is made more difficult by weak physical condition, associates with increased risk of infections and skin problems, all affecting many aspects of leading a normal quality of life at work, with the family and more generally in society.

5. GP knowledge of `living with incontinence' is sometimes good, sometimes patchy.

6. There appears to be insufficient access to trained continence nurse specialists and a lack of specialist continence clinics.

7. All attendees reported that they have to purchase their continence care products privately, some being partly or mainly supplied with free NHS products, to the extent that the PCT policy is not clear and/or does not appear to be applied consistently.

Recommendations

1. Information about free, professional incontinence services, should be made more readily available, from the CCG, GP practices, Social Services Departments, the Continence Advisory Service, The Urology Team, the voluntary sector and others.

2. Condition-specific advice should be more readily available, wherever this may be appropriate. All advice should be patient-centred, rather than service-driven.

3. Continence Advisory services should be provided in the context of how better management should help to reverse the risk of `spiral of psychological and physical decline'. It should more often be delivered in a multi-disciplinary context. More preventative activity should be commissioned, to anticipate the changing options that some patients might require and to minimize in particular the risks of psychological decline, social withdrawal, urinary infections and skin problems.

4. GP training in the subject of `Living with Incontinence' should be improved.

5. The number and availability of Continence Nurse Specialists and Specialist Continence Clinics should be reviewed and improved to meet need. Service delivery could be better coordinated and better resourced or better deployed, or both.

6. The Berkshire West PCT policy on the provision of free continence care products to those in need should be made available in the public domain and then needs to be reviewed as to content, appropriateness, relationships between quality and clinical value, consistency of current compliance and possible improvement.

7. Embarrassment surrounding incontinence need to be lowered, an opportunity for the incoming Clinical Commissioning Groups, GP practices, the Continence Advisory Service, the Community Neuro-rehab Team, the voluntary sector and others.

8. This report should be circulated to local statutory sector commissioners and providers involved with services for people who may be affected by incontinence.

9. The need for a Continence Advisory Service review and upgrade is indicated and the findings of this report should be the basis of a larger survey, to inform that review. Such a survey need not be restricted to the needs of the neurological sector.

For further information about this focus group please contact:
John Holt,
West Berkshire Neurological Alliance,
2, Clayhill Crescent,
Newbury
RG14 2NP
johnmholtbsc@aol.com
Tel: 01635 33582
www.wbna.org.u k

Notes taken by the first independent recorder
Focus Group Meeting — 27th March 2012

Living with Incontinence

The convenor introduced the discussions by suggesting there seems a mixed bag of information available on living with continence. The following discussion then evolved:

PD Problem of co-ordinating bladder emptying with the `on/off' situation. When the drugs wear off it is more difficult to cope. This lady has had no incontinence advice — she has learned to manage by trial and error and prepares herself by emptying her bladder at every opportunity.

MS `People need to ask for help.' The help is probably there but many people feel the problem isn't serious enough to go to the GP about, and feel it is something that they must learn to live with.

MS Botox is sometimes used to help bladder control, also Oxybutinin helps to control and reduce bladder spasm. Some people need to take an antibiotic every night to thwart urinary infections, which in turn can lead to stones forming. The MS can blunt sensations so that you do not always realise that you need to empty your bladder.

Post Polio Needs to wear pads all the time because started leaking from bladder and then bowel. She has no sensation of bowel movement but knows when she needs to pass water, but leaks as well. Has had kidney infections and leakage. Doesn't know if it is a spinal problem or whether the sciatic nerve is pressing on the bowel and bladder or something else. Requested a visit to see a neurologist but had to wait 4 months for an appointment.

MS This person has discovered that a glycerine suppository and laxatose has helped her, but discovered this for herself — no one advised her.

PD Problem of passing water and leaking from the bowel at the same time — when constipated, she doesn't get this bowel leakage. Diet affects the bowel movement. Lactulose makes her too loose. (Fibrogel is meant to ease constipation but can have the reverse effect on some MS patients.)

PD PD drugs tend to make you constipated. Can only pass motions when `on' drugs. Very difficult when `off' drugs because you can't get the pants down with one hand, balance problems mean you have to hold on to something at the same time.

One person suggested that a jar of cherries from Waitrose mixed with bran helped with the constipation problems.

Prompt: How do people get their information and help?

From friends, sometimes a GP, a urologist, support groups such as Polio Fellowship.

PP Comments from the PP carer that the specialists don't talk to each other and he would like there to be a case conference involving all the professionals who could discuss all the different problems affecting his wife as a result of this condition. Point made that there are as many people with polio as PD. Constipation and depression are just as important as the motor problems in PD. Complaint that neurologists don't talk to other professionals.

PD Some GPs don't know much about PD and resent the cost of the drugs required.

MS MS carer pointed out that, with advice, certain things can be done by carers at home e.g. bladder washout and catheter care. This can save everyone time, inconvenience, urinary infections and money.

Epilepsy (by proxy) Seizures cause incontinence. If epilepsy can be controlled, then the incontinence can be controlled. If you see the right clinician you get the right treatment, but how do you see the right clinician?

MS Lots of people with MS have bladder problems and these can lead to complications with the kidneys.

Prompt: Cost of incontinence

Time and fatigue. There's also a financial cost — pads can cost a lot of money and the NHS does not always supply them. When does the NHS supply them for free?

The incontinence issue affects people's quality of life, sometimes, to a disproportionate degree. 'I would prefer to have a shorter life of good quality than a long life of poor quality'

Summing up

Incontinence is a hidden condition that can lead to many awkward and embarrassing moments. It is a serious challenge to good relationships between couples.
It can be expensive — not only the cost of pads, but also the various 'remedies' that are alleged to help.

Do we have enough continence nurses? Probably not as so few people seem to have seen one.

'It is scary that people do not know enough about incontinence.' Neurology patients have these symptoms which are not seen (especially in younger people) and therefore ignored by the medical profession

A clinic is needed that specialises in Neurology patients and ALL their problems, including incontinence. People should have confidence in discussing this subject.

At the end, the participants said how helpful it was to discuss the issue with others experiencing similar problems.

Notes taken by the second independent recorder
Focus Group Meeting — 27th March 2012

A group of people with various neurological conditions met to discuss the problems they face as a result of incontinence caused by their illness.

A very strong message that was expressed repeatedly was the lack of information about what is available or, when the subject is discussed, how appropriate is the information?

Comments from individuals

- Inability to get to the lavatory in time. District nurse suggested a catheter that the patient found unacceptable.
- Loss of sensation. District nurse suggested a suprapubic catheter, which idea was strongly resisted.
- Has had no advice from the medical profession.
- `No one can cure us', so it was felt that the inclination was for professionals to dismiss the problem.
- Patient with Parkinson's disease said when Levodopa is working she has control but none when the effects from the drug wears off. She has had no advice from the medical profession.

It was suggested that women find the problem easier to discuss than men because of the additional embarrassment men probably feel.

When help has been available, the following were examples;

- Catheter tuition
- Botox injections
- Oxybutynin which reduces bladder spasms.

<u>Leading an active life</u>

- `Some of us are young'. The medical profession sometimes appears not to care about the quality of life, only the length.

Costs

- `The underlying disease makes you very tired and it takes longer to deal with problems.'

- 'When continence products are supplied there is not enough to last until the next delivery so one has to buy more.'
- 'Many necessities have to be paid for. They should be free.'
- 'One does not necessarily qualify for financial help.'
- 'One does not always qualify for Disability Living Allowance.'
- The underlying disease is a serious challenge to relationships.
- The disease has caused the husband (carer) to drink more gin!

Problems encountered

- An M/S sufferer has no sensation in her bowels and sometimes defaecates spontaneously.
- A polio survivor had a problem of first leaking from her bladder and then her bowels. She found this very distressing, as she is very fastidious. It lasted about a month but she suddenly became very ill with a bladder infection. She has no sensation in her bowels.
- Suppositories work, but timing is critical so that the resulting bowel movement is at an appropriate time.
- 'My bowels leak without a full bowel movement.'
- 'Parkinson's disease drugs make you constipated. When the effect of the drug has worn off, it is difficult to do anything for oneself.'
- Drugs affect people differently.
- Neurologists and Urologists do not talk to each other. It would benefit patients if they did.
- Drugs cost a lot and doctors worry about their budgets.
- Catheters block. Carers should be allowed to do a bladder washout. In one instance the consultant agreed but the GP refused consent and so the consultant's signature had to be obtained.
- The husband of an incontinent person worries about the problem that would occur if he became ill.
- 'Some of us are young, so there is a large, long-lasting economic burden.'
- Are there enough continence nurses, as some of the group have not seen one?
- The risk of bladder infection can be high and this can make patients very ill.

- Kidney stones can occur when there has been a bladder problem.
- 'Is commissioning going to affect support?'
- 'If you see the best consultant, you are lucky.'

The participants commented that they had found the afternoon's discussion very useful.

Conclusions

There are large numbers of people with neurological disease and there should be more support to help them deal with the inevitable problems that occur.

It is a matter of luck as to whether a patient sees the best consultant, but when that happens much useful support can be gained and life made easier.

When a continence nurse is available she can be very helpful. Unfortunately there are not enough of them.

Appendix 2

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition
Health and Social Care awards winner 2008 'Leadership for Improvement'

2, Clayhill Crescent, Newbury RG14 2NP
01635 33582 johnmholtbsc@aol.com

August 2012

To all local individuals living with or affected by incontinence,

Anonymous survey of local people living with incontinence

We are inviting anyone interested to complete a survey form that we have helped to devise in co-operation with West Berkshire Local Involvement Network (LINk) and others. The survey will take place across West Berkshire, Reading and Wokingham. Everyone who responds will be showing a commitment to improving services for others, so thank you if you decide to take part.

We appreciate that for many people the subject of living with incontinence is about very intimate matters that may be too embarrassing to discuss with other people. For that reason we are not asking for any personal information from anyone who takes part. Your answers will be completely anonymous. The replies will be analysed by West Berkshire Local Involvement Network (LINk). A report will be published on our web site www.wbna.org.uk and elsewhere. The findings will be used to help inform local NHS and social care managers about how to plan and commission better services in the future.

I would be most grateful if you would complete the form enclosed and return it to WBILN, 4-8, The Broadway, Newbury RG14 1BA in the pre-paid envelope provided, at your earliest convenience. If you have any questions or need help to complete this survey please contact me on johnmholtbsc@aol.com or 01635 33582.

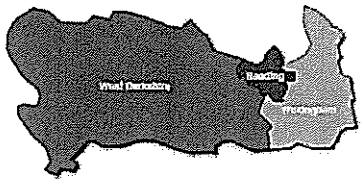
Should you wish to complete the enclosed Healthwatch leaflet with your contact details, that leaflet will be processed entirely separately from this survey.

Thank you for your help and support.

Yours faithfully,

John Holt Liaison Officer
West Berkshire Neurological Alliance

Your voice on local health and social care



West Berkshire
Neurological
Alliance
Registered charity no 1081021

Living with incontinence survey 2012

This survey is for people living with incontinence who live in, or use NHS services in the area covered by NHS Berkshire West. The information will be analysed by an independent organisation and recommendations published widely. Please answer the *questions by ticking your answers and writing in the comments boxes.*

1. From the map above do you live in: West Berkshire[_] Reading[_] Wokingham[_]

2. Are you: Male [_] Female [_]

3. Is your age: Under 18 [_] 18-34 [_] 35-49 [_] 50-65 [_] 66-80 [_] Over 80 [_]

4. Which of these affects you, and how much?

	Not at all	Sometimes	Quite a lot	Most or all the time
Bladder incontinence				
Bowel incontinence				

5. Do you think your incontinence is linked to a particular condition? Y [_] N [_]

(if yes, please state) .....

6. Generally, how well are you able to manage your incontinence?

Not at all |_| a little |_| some of the time well |_| almost all the time |_|

7. Do you believe you have all the information, help and advice you need to manage your incontinence as well as you ever could?

Please add here any comments about your answers to questions 4 - 7

8. What impact does your incontinence have on any of the following?

	Very Negative	Negative	Small or no impact	Positive	Very positive
My general physical health					
Condition of my skin					
Bladder infections					
My psychological outlook					
Leading an active life					
My quality of life					
Personal relationships					
My self-esteem.					
Being fulfilled					
Other (please state)					

Please add here any comments about your answers to question 8

9. How easy is it to find the following things that you may need?

	Easy	Fairly easy	Not very easy	Difficult
Timely and suitable information				
Timely and suitable advice				
Effective management options				
Effective products that suit me				
Effective support				
Ways to adapt to change				

Please add here any comments about your answers to question 9

10. How much do you agree or disagree with the following statements?

	Strongly agree	Agree	No view	Disagree	Strongly disagree	Not app
The NHS Continence Service is easy to contact						
The NHS Continence Service is well run						
The NHS Continence Service is well resourced						
I get all my continence care products free from the NHS						
The NHS products I use are the right quality for me						
It is easy to order or reorder continence care products from the NHS						
I have enough space to store my continence care products						
I am given appropriate continence care prevention information from the NHS						

Please add here any comments about your answers to question 10

11. How well do these understand and help you with your incontinence needs?

	Not applicable	Not at all	Small extent	Quite well	Very well
GP					
District / Community nurses					
Continence advisor					
Specialist Continence clinic					
Urology or bladder specialist					
Other hospital staff					
Physiotherapist					
Psychological support worker					
Occupational Therapist					
Social Services Care Manager					
Voluntary sector					
Other *(please specify)*					

Please add here any comments about your answers to question 11

12. What else would you like to say about 'Living with incontinence? What changes would you suggest, if any, to the way services are provided to people affected by incontinence?

My suggestions ...

13. Which statements best describe your mobility situation? *(please tick up to two)*

I am able-bodied, without any mobility impairment [_]
I use a walking aid [_]
I am a wheelchair user [_]
I am confined to bed [_]

14. Which of these applies *(please tick one box only)*

I filled in this form myself [_] Someone helped me to complete this form [_]

Thank you for completing this survey. Please return it in the envelope provided to:
West Berkshire LINk, 4-8 The Broadway, Northbrook Street, Newbury RG14 1BA

For further information please contact:

John Holt,
West Berkshire Neurological Alliance,
2, Clayhill Crescent,
Newbury
RG14 2NP
johnmholtbsc@aol.com Tel: 01635 33582 www.wbna.org.uk

West Berkshire Neurological Alliance

Representing all people in Berkshire West affected by a neurological condition
Registered Charity No: 1081021

Appendix 3

Conditions that people felt were linked to their incontinence problems

1	Parkinson, too much botox to bladder
2	MS
4	Astrosytoma T4 Complete
5	Ulcerative Colitis
6	Stroke
7	Alzheimer's disease
8	Dementia (Corticobasal Degeneration)
9	Spinal Cord Injury
10	The bladder is very small and cannot be enlarged any more
11	Dementia
12	Probably Parkinson Disease
13	Parkinson Disease
14	Cancer of Colon Operation
15	Motor Neurone Disease
17	Fracture of CS/6 + Head Injury in RTA
18	Alzheimer's and Slow Mobility
21	Child Birth
23	Depression and alcoholism
24	Alzheimers
25	CVA
26	CVA

Appendix 4

Trust helping victims of the 'silent epidemic'

The Trust was among the first in the country to pioneer a new method of treating the "silent epidemic" of Stress Urinary Incontinence which commonly affects new mothers.
The traditional treatment for bladder weakness involves a stay in hospital for surgery followed by up to a month
recuperation. However, our Urology Department now offers an alternative and highly effective treatment. Patients undergo a minor procedure to have a special gel injected to help the bladder muscles – normally they will be in hospital no more than a few hours and should be able to return to normal life in a couple of days. Already around 500 women have benefitted from the new treatment.
Consultant Urologist Steve Foley said: "SUI is a silent epidemic that women are really scared to come forward and talk about. Injection therapy is a quick and simple procedure to rectify the problem."

Royal Berkshire Hospital - Pulse Winter 2012/13

Appendix 5

Mon 04/02/2013 07:43

Tony

I don't think I have anything to add to this report, though I do believe that those with bladder and/or bowel dysfunction are grateful for a comprehensive assessment from a continence specialist nurse precisely because they do explore a range of conservative treatment options and strategies before suggesting containment as a last resort.
You may or may not know, too, that every six months we organise a flyer distribution to all GPs in Berkshire, the last was at the beginning of January, please see attached, which very briefly describes our service and identifies how they might refer to us. We also organise an extensive training programme throughout the year of full day courses and half day updates on subjects such as continence promotion, continence assessment, catheterisation and bowel dysfunction which is open to all community and practice nurses and GPs, too, of course if they can spare the time.
Furthermore, we have formed close links with the specialist nurses and consultants in MS, Parkinson's Disease and other neurological conditions in Berkshire so that if and when they reach the limit of their expertise in bladder and/or bowel dysfunction they may refer directly to our service.
I'm sure the exchange of information and ideas will inform our service in the future.

Kind Regards,

Terri

Terri Dunbar
Continence Services Manager
Berkshire Healthcare NHS
Foundation Trust

0118 949 5232

Continence Advisory Service
Wokingham Community Hospital
41, Barkham Road
Wokingham
Berkshire
RG41 2RE

teresa.dunbar@berkshire.nhs.uk

Appendix 6

Continence Advisory Service

Did you know?

We have a Berkshire-wide Continence Service for patients with bladder and bowel dysfunction

All we ask is that they are motivated to follow a treatment programme to regain their bladder or bowel function

Treatments offered after a specialist assessment include:

- Pelvic floor re-education
- Neurostimulation
- Biofeedback
- Bladder & bowel re-training programmes

Clinics are held in the following venues:

- Upton Hospital
- St Marks Hospital
- Skimped Hill Health Centre, Bracknell
- Wokingham Community Hospital
- Royal Berkshire Hospital
- West Berkshire Community Hospital

Referrals can be sent on the attached referral form to:
The Continence Advisory Service
Wokingham Community Hospital
Barkham Road, Wokingham, RG41 2RE
Tel: 01189495146
Email: continence@berkshire.nhs.uk

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Your voice on local health and social care

West Berkshire Local Involvement Network

Royal Berkshire Hospital Dignity and Nutrition Study 2012

Authors

Tony Lloyd - Chair West Berkshire LINk

Man Liu Clarke – LINk support officer

Feb 2013

Contacts

Man Liu Clarke

Broadway House
4-8 The Broadway
Northbrook Street
Newbury
RG14 1BA
www.westberkshirelink.com

Tel 01635 760425
linksadmin@wbiln.com

Tony Lloyd

tonylloyd25@googlemail.com

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1 Background

Concern had been expressed by the West Berkshire Council Health Scrutiny Panel (HSP) on July 19th 2011 about the lack of up to date information available to councillors on Dignity and Nutrition at the Royal Berkshire Hospital. This was in part due to the fact that the CQC had undertaken a series of visits at 100 hospitals across England on these topics which did not include the RBH.

At the HSP meeting on October 4th 2011, the West Berkshire LINk undertook to investigate these topics and to provide an interim report to the HSC by mid January 2012.

In this study, working in collaboration with the Princess Royal Trust and Crossroads, 250 questionnaires were despatched and we had 51 valid responses (20%)

32 responses related to inpatient episodes at the RBH with the remainder relating to Basingstoke (7), Swindon (4) Oxford (2) and a variety of other hospitals. The bulk of the responses (65%) were from people in the RG14, RG19, RG31 and RG18 postcodes

Bearing in mind those caveats, there was evidence that many people using the RBH were content with the standards of care that they had experienced. However 15% of that sample would not recommend it to a friend which was a concern. It was noted that this rose to 20% if the episodes at other hospitals was taken into account. The RBH, by way of contrast, reported that their performance on the "recommendation" question had improved from 89% to 94% from 2010 to 2011 on the basis of their internal rolling monthly survey.

It was recommended that the survey be expanded to a wider group of patients preferably by obtaining the direct cooperation of the Royal Berkshire Hospital in sending out similar questionnaire packs to a random sample of people aged 65 or over that have been discharged from any ward in the last 6 months.

Working with the cooperation of the Royal Berkshire Hospital 500 questionnaire packs were prepared and handed over to RBH management. These were then distributed to adult wards in the RBH to be handed to patients aged 65 or over on discharge from the Hospital, irrespective of where they lived.

2 Recommendations

Despite all the additional measures taken, this study is far from ideal. The response rate is low, the number of replies from patients on some key wards was one or less and one in eight responses were for people experiencing day surgery. Despite these caveats, there

are grounds for making the following assertions and recommendations with some degree of confidence

a) As in the first survey, most patients are happy with the services provided. There is no evidence of any systemic failings in care provision. It is, however, recommended that this survey should be repeated from time to time and that the RBH should be asked to suggest better ways of distributing the questionnaires.

b) There are, however, a small number of examples of **very poor** practice at the RBH. Senior managers will almost certainly be aware of similar issues in the past. One or two of these, if true, are so bad that they could constitute a serious risk of harm to patients. It is recommended that these issues be referred to the relevant Care Group Boards so that measures can be put in place to reduce the risk of recurrence.

c) It is recommended that RBH senior managers review, with front line staff, the processes for the recruitment, training and supervision of healthcare assistants and agency staff. Ward managers must be enabled and empowered to invoke standards of patient care on their wards that are intolerant of the few aberrations referred to in this report and to exclude those who are unable or unwilling to perform to a satisfactory standard. They should also be empowered to report upwards without fear of recrimination if they are understaffed or unable to provide an appropriate standard of care.

d) It is recommended that catering staff should be required to place food and drinks well within the reach of patients and that uneaten food should not be cleared away without a) asking the patient what was wrong with the food or b) without recording that the patient had refused the food.

e) It is recommended that **all** GP surgeries be required to arrange for an independent anonymous survey to be done of a random sample of referred patients each month covering the same issues that this table covers. It is further recommended that the patient participation groups be encouraged to review the returned surveys and either write reports or make recommendations to GPs (or the CCG) accordingly.

3 Detailed Report

3.1 Demographics

The total number of responses was disappointing. Out of 500 questionnaires taken to the RBH the total returned amounted to only 94 or 19%

In some cases it was the carer or relative who completed the survey (some didn't answer the question)

68	76%	A. The patient
0	0%	B. A carer
22	24%	C. A relative or close friend of the patient

The age profile of the patients was :-

4	4%	A. 65 or less
57	61%	B. 65 or over
32	34%	C. 81 or over

And the gender of the patients was :-

43	47%	Male
49	53%	Female

The patients came predominantly from the Western half of Berkshire (based roughly on postcodes)

Reading	27.7%	26
West Berkshire	24.5%	23
Wokingham	24.5%	23
South Oxfordshire	8.5%	8
Bracknell Forest	8.5%	8
Maidenhead	2.1%	2
Hampshire	1.1%	1
Not Stated	3.2%	3
		94

2.2 Distribution of Wards

It was intended that the questionnaires would be distributed across all of the adult care wards. However the actual distribution of responses was as set out below:-

A&E		3
Adelaide Ward		3
Adelaide Annex		1
Adult Day Surgery Unit		9
Burghfield Ward	E	0
Cardiac Care		4
Castle		2
Caversham		3
Chesterman		1
CDU		7
Dorrell		1
Emmer Green	E	3
Heygroves Ward		0
Hopkins		2
Hunter		1
Hurley		2
I.C.U.		1
Jim Shahi		4
Kennet		4
Lister		0
Loddon		3
Mortimer	E	4
Oakwood		2
Outpatients		1
Redlands		1
Sidmouth		3
Sonning		4
Stroke Unit		8
Trueta		1
Victoria		6
Whitley		2
Woodley	E	4
Unstated		4
		94

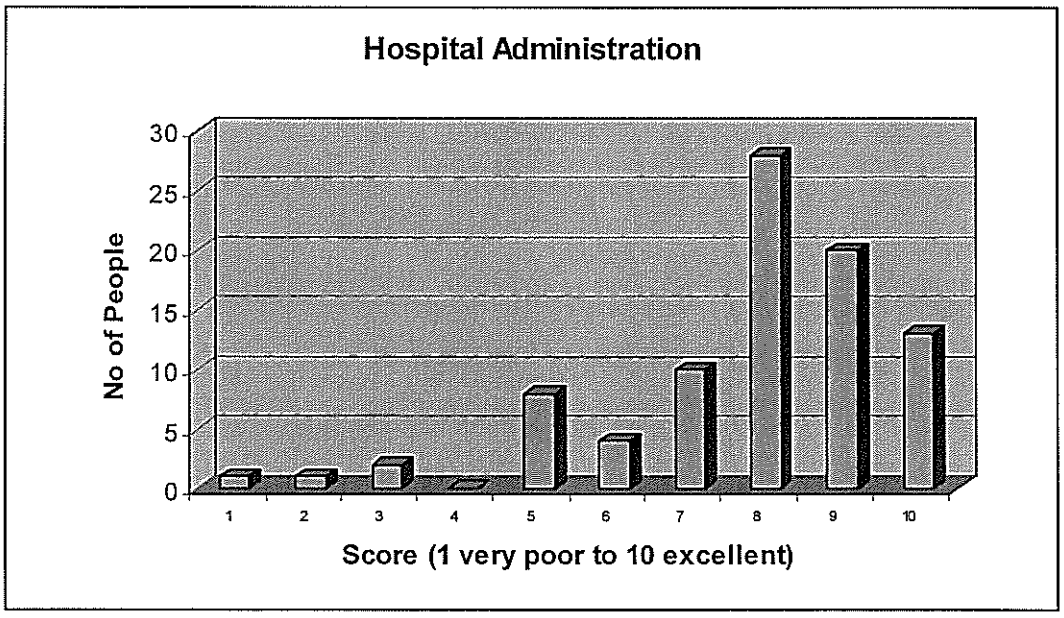
Only 11 of the questionnaires were completed by patients who had been on the 4 elderly care wards (marked E in the table above) whereas 9 had been returned from the adult day

surgery unit, 1 from outpatients and 3 from A&E. In other words 13 of the 94 were from patients who hadn't even stayed overnight. This was disappointing.

3 Outcomes

3.1 Administrative Support

The bulk of patients had experienced few problems but a small minority had had a poor experience. The following chart shows the variation



The majority of patients were complimentary

1) *I found my time on Victoria Ward a very pleasant experience as all staff were very attentive to patients' needs at all times.*
2) *No complaints at all. All staff were very kind. (A&E)*
3) *Seemed to run smoothly (Sonning)*
4) *Very well organised (Jim Shahi)*
5) *Excellent (ADSU)*
6) *I was very impressed by the care and attention given by the entire staff. Very well done. (Cardiac Care)*
7) *Most of staff very helpful (A&E)*
8) *Discharge was quick and therefore a little confusing. We were taken to our surprise to the discharge lounge which was 5 star. (Kennet)*

But there were some adverse comments about discharge

1) *Discharge process was difficult. Time of discharge changed, this caused problems as elderly patient needed to have someone at home to settle her back in. Discharge lounge staff did though solve the problem. (Stroke Unit)*
2) *Discharge unreasonable delay waiting for medication from pharmacy. (Hurley)*
3) *Admissions very good, Discharge to another hospital - long winded communications, frustrating.(Hurley)*
4) *Discharge - not so good (9.30 told by Dr I could go home. Ward seemed to have everything organised, but just waited for medication. Stayed on ward in very unconfortable chair for the whole afternoon. After 5pm, moved to Discharge Lounge. Why couldn't I have gone there much earlier? It's brilliant! Was out within 30 minutes with medication.(ICU and Victoria)*

And some others about communications

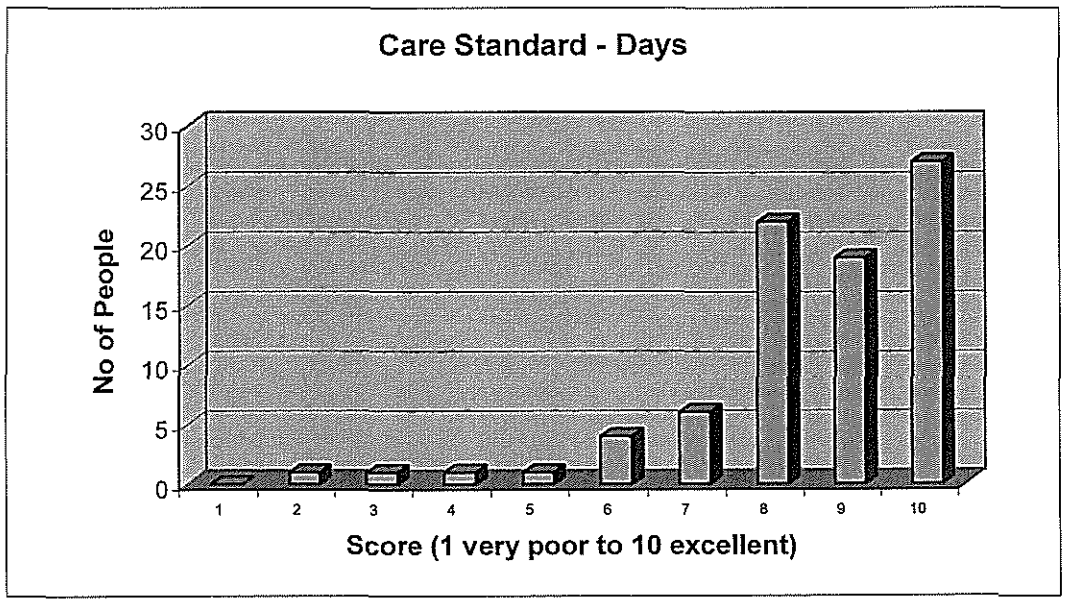
1) *Very difficult to communicate by phone to confirm appointment. Impossible to understand the message on the answerphone. In spite of leaving 3 requests on this machine for a call back, none was received. (ADSU)*
2) *There was a mix-up with initial request for appointment due to length of validity and then ended up with a 'double booking'. Communication on the ADSU ward was good.(ADSU)*
3) *Admission confused; kept telling us Dad could go home and then changing their minds; forgot to get care package re-started; forgot to put medicines in a NOMAD. (Loddon)*
4) *Felt communication was a bit lacking as the reason my operation did not go ahead.Had been present several weeks earlier and could have been sorted earlier so the operation could have gone ahead on the scheduled date. (Trueta)*
5) *There was a lack of communication. My family were told conflicting information and in the end had to request to see my oncologist. Results of tests not passed on etc. (Adelaide)*
6) *Letter received on Monday cancelling an appointment on previous Friday (Jim Shahi)*
7) *Communications - I am deaf and was admitted with a Meniere attack so my head was very dizzy. Doctors and nurses kept giving me information I could not process at the time rather than speaking to my family when they visited as requested. (Loddon)*

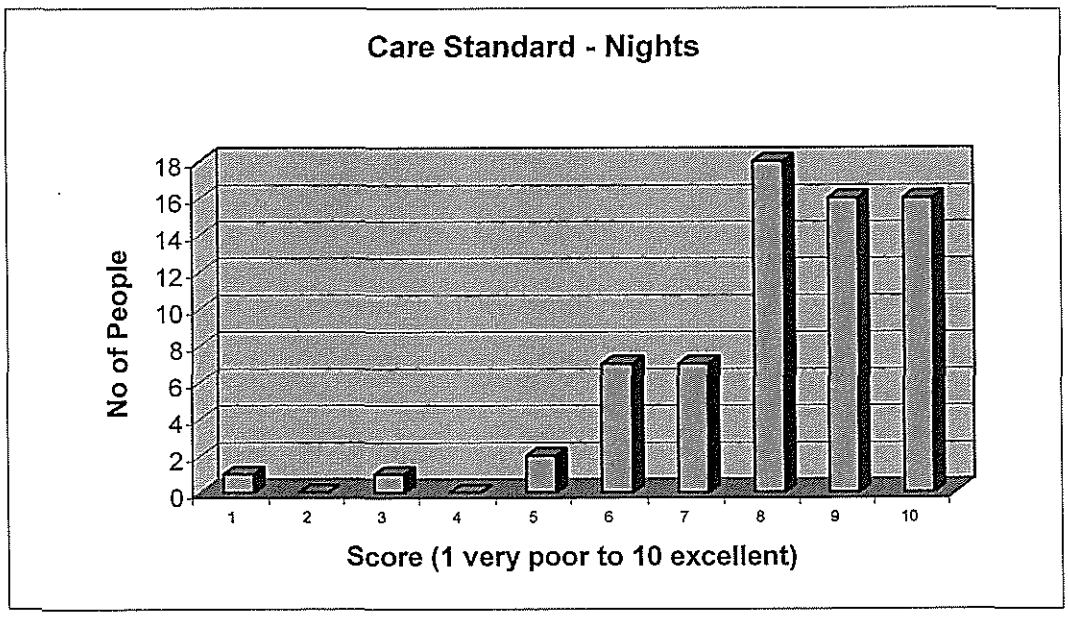
And about delays

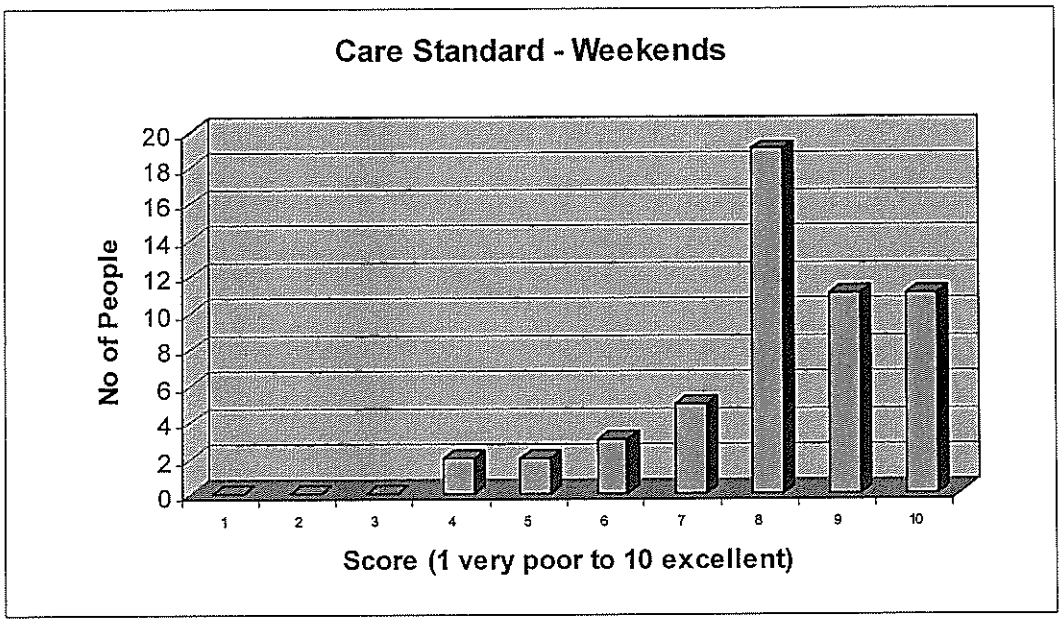
1) *Thought admission was disgusting. I arrived at A&E at 3pm and eventually put to my ward at around 1am. (Sonning)*
2) *The only thing I was disappointed in was he was left to wait in the care home for 6 hours sitting in a chair. (CDU)*
3) *Discharge was a long wait for medication. The score would have been 10. (Redlands)*
4) *Firstly, I am disabled and rely on my wheelchair. I had been discharged on the Friday following a stay of 16 days with a kidney infection. As I was still unwell my GP called the hospital and advised that I should go straight to CDU. On arrival, to CDU it was a shambles and we had to go to A&E who sent us back to CDU*

3.2 *Standards of Care*

We asked patients about the Standards of Care that they had experienced during weekday days and evenings and at weekends and received the following responses where 1 is very poor and 10 is excellent. In the main, patients were complimentary but there is evidence that a small minority were much more critical and that there is a marginal deterioration in standards in the evenings and at weekends.







As can be seen from the graphs, many patients were pleased with the standards of care that they received.
Complimentary comments received about day care included:-

1) Very good care. Kept informed at all times. Staff excellent and very caring. (Cardiac Care)

2) Excellent care given.(Victoria)

3) Very courteous and considerate (Stroke Ward)

4) Excellent (ADSU)

5) First class care and food (Kennet)

6) Once again doctors and nurses, the entire staff were all super, very caring and touching. Could not ask for better. So lucky to have them.(Cardiac Care)

7) I have spent many days and nights through the Royal Berks cancer wards in the past 5 years. Excellent care. (Jim Shahi)

There were few favourable comments received about night and weekend care but these few included:

1) Extremely caring and efficient nurse in duty (Sonning)

2) The staff were very considerate and helpful when I reached the ward at about 10.30 (Hopkins)

3) Just as above, faultless, attentive, caring, true public angels of the night. Truly great team. (Cardiac Care)

4) The night staff, no matter how busy, had time for you, and if you needed help in any way did so, and when you rang the bell, came as soon as possible and explained if could not see to you then. Not like day staff, most of them would turn it off and not come back.(Woodley)

However there were a minority of unfavourable comments on days. Some of these are cause for concern (see 6 and 7)

1) Poor. Badly managed, little communication with patients. (Hurley)

2) Very slow when asked to go to toilet and very slow to return (Mortimer)

3) During his stay on Loddon ward no-one ensured that Dad drank enough and as a result he developed chronic constipation on discharge, needed to have an enema and be re-admitted for 24 hours.

4) When my mother wanted the bedpan, she would have to wait over half an hour.(Mortimer)

5) The staff didn't all understand when patient is visually impaired they won't know where water/food is, or see body language.(Mortimer)

6) For myself, I was left to sort myself out which wasn't very easy. There were 5 other beds in the bay. Two of those beds had ladies of 91 in. In the morning the drink was put on their table, not pushed to them and left as was the case with their breakfast. These ladies neither ate or drank anything and the domestic staff came and took the dishes away not checking why nothing had been consumed. It was the same throughout the day and was only when relatives came that they were fed and watered. Appalling scenario.(CDU)

7) One lady in white. As I was in a lot of pain I could not have any pain relief. She had no authority to say so and she bullied me and another lady she had like me in tears. I did tell the sister, asked the lady's name, at first she said she did not know it. I said I'd find it out with that sister told me so I could write a complaint. Has no apology. (Woodley)

And a few more on nights and weekends

1) No night care.(CDU)

2) Few staff - generally abrupt and unsympathetic (Hurley)

3) Woken up too often in the night (Mortimer)

4) You let yourself down at weekends. No where near enough staff on duty i.e. when my wife needed to go the toilet it took 15 to 20 minutes to assist her.(Calcot and Caversham)

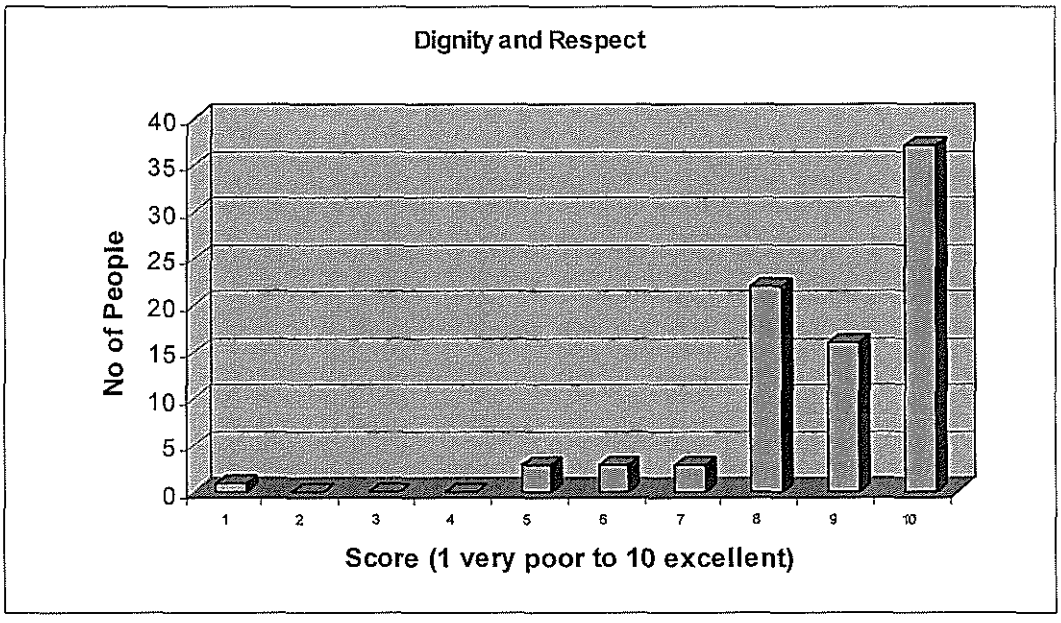
5) Mum not always dressed, no physio, and not enough nurses to attend patient alarm.(Mortimer)

6) Diabolical. No pillows available and in the end nurse took one from behind another patient and went to put it behind me. I let it be known that it needed cleaning. I was not given a water jug until I had asked for it 4 times and it was now 2:20am. There was a male bank nurse working who really shocked me. One of the old ladies was trying to get out of her bed and he just laughed and said he was busy. I shouted to another nurse to help and this happened twice. Throughout the night he would sit himself at the computer at the end of the ward, eat and drink and laugh at whatever he was watching. I was appalled. (CDU)

7) My mother fell while getting out of bed and broke her wrist. We've had several stories on how this happened, we would like the truth. (Stroke Unit)

3.3 Dignity and respect

We asked people if they felt they had been treated with dignity and respect during their stay and had pretty much the same profile.



Though many of the comments received on this section did not directly address the topic, but rather the standard of care, those that did were invariably favourable:

1) *I was treated with dignity, respect from every member of staff (Jim Shahi)*
2) *Very difficult to maintain dignity in hospital, but staff tried (CDU)*
3) *I was treated with utmost respect.(Victoria)*

There were a minority of lapses though

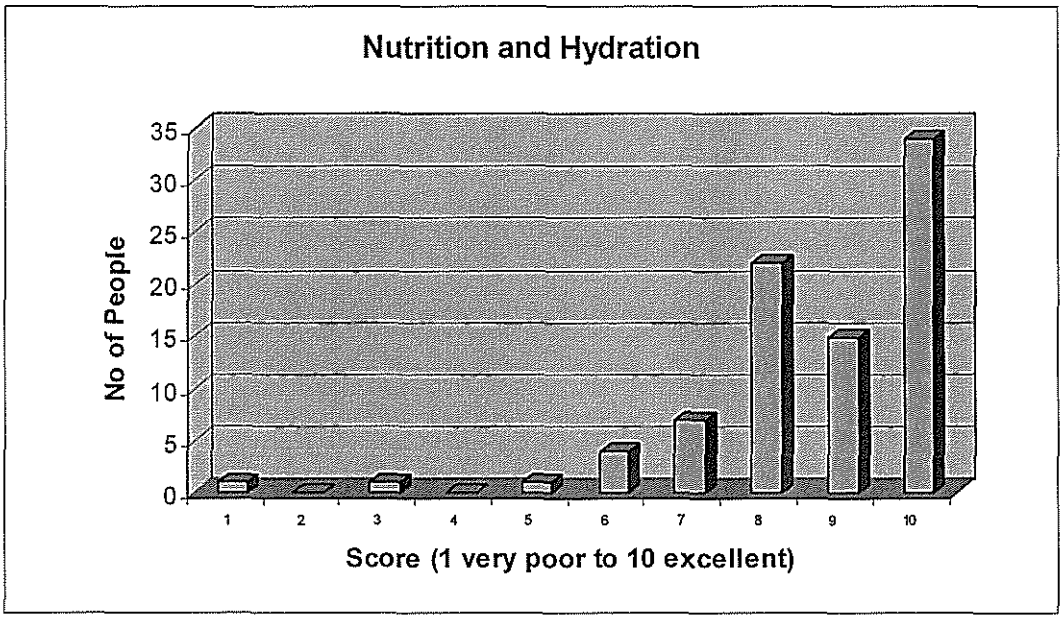
1) Generally OK, but they threw my mothers clothing over the privacy curtain and left them there until my mother struggled to get them and then they screwed them up and squeezed them into the cupboard and then did not dress her for a day.(Mortimer)

2) Dad felt that the staff did not treat him with respect. Certainly many did not answer the questions that he had regarding his care.(Loddon)

3) I was under the care of at least 10 nurses during my stay in hospital and only one nurse was a bit impatient and abrupt verbally to me. I'm sure she might have been having a bit of a bad day, like we all do at times.(Stroke Unit)

3.4 Nutrition and Hydration

Much the same applies to patient's experiences of nutrition and hydration.



Patients comments were almost all either favourable or neutral though invariably you can't please everybody.

The favourable ones included:

1) *Food service very good.(Emmer Green)*
2) *Lovely food, far too much for me. (Stroke Ward)*
3) *Good selection. (Castle)*
4) *Tea and toast provided after surgery promptly.*
5) *Much appreciated as xxx is insulin dependent diabetic. (ADSU)*
6) *Food was excellent. (Mortimer)*
7) *Food and drink good. (Mortimer)*
8) *The best part was the food, it was very good and very varied.(Woodley)*

The critical ones included:

1) *Much of the food was unpalatable. (Hurley)*
2) *Poor menu for cancer patient. (Adelaide)*
3) *Dietician recommended a low salt diet and said 'no gravy, no cheese, no ham' etc. Unfortunately the menus did not indicate 'low salt' neither did it have clear options with no gravy, cheese etc - I would have to eat salad or a sandwich all the time. Not good on a cold day.(Loddon)*

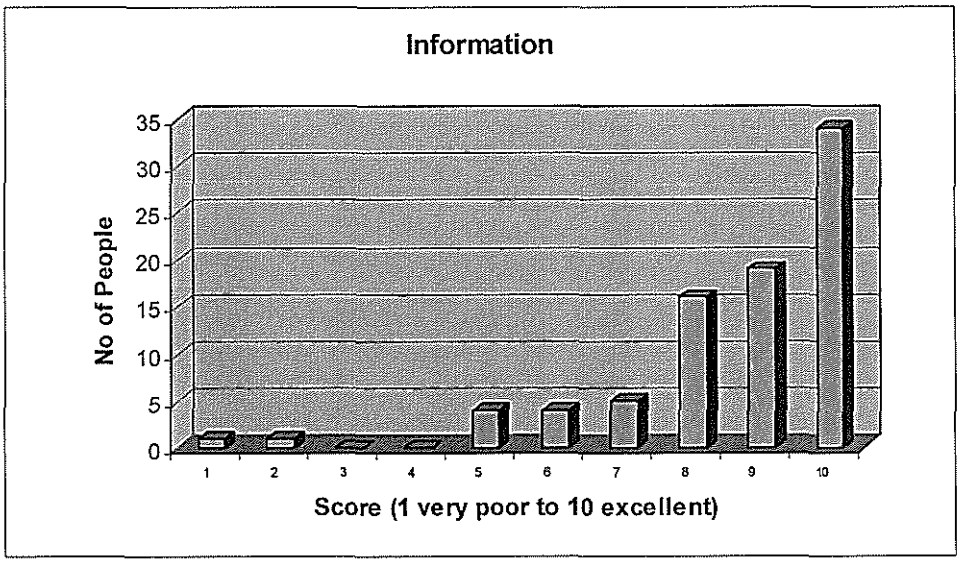
Nobody specifically stated that they (personally) couldn't access the food though there were comments about hydration.

...., getting refreshment bearing in mind I was still dehydrated, was a struggle. (CDU)

.... Not enough to drink. No checks on when Dad had last 'done a No.2' (Loddon)

3.5 Information

Again as can be seen from the graph, the majority of people were satisfied with the level of information received but there were exceptions.



The complimentary comments included

1) *Kept informed at all times about treatment. (Cardiac Care)*
2) *All treatments were explained to me. (Victoria)*
3) *It could not have been better (Sonning)*
4) *My score says it all - Excellent!! (Stroke Unit)*
5) *Before procedure saw both consultant and anaethetist - good info. (ADSU)*
6) *The consultant took his time to explore and make sure I understood, this was done with the utmost care for me as a patient. (Jim Shahi)*
7) *Perhaps the information conveyed could be less technical, but on the whole I was satisfied with answers to my questions.(Hopkins)*
8) *Both consultants and junior doctors kept me fully informed about my treatment, and importantly LISTENED! (Hunter)*

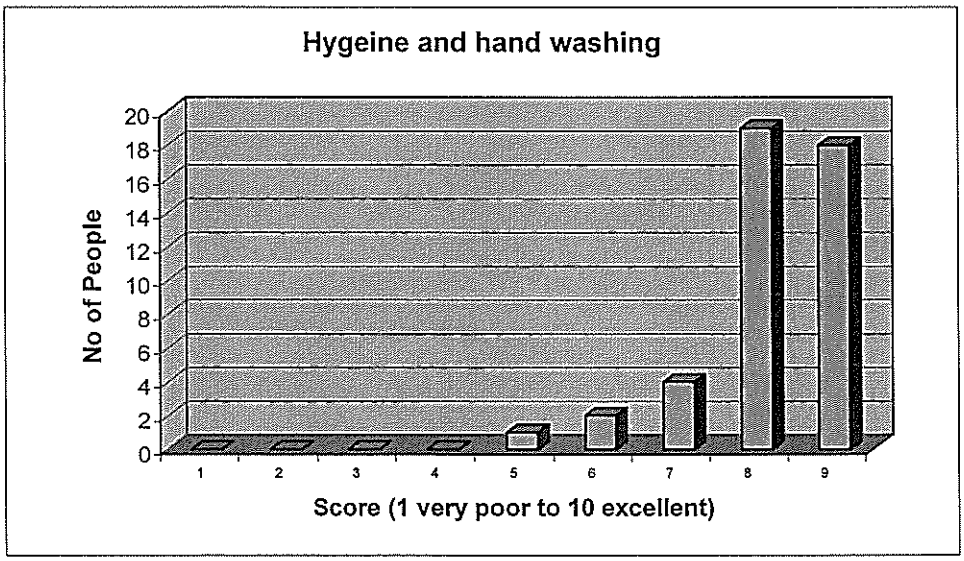
The exceptions included

1) *Would not tell you what was wrong. (CDU)*
2) *Poor - lack of communications (Castle / CDU)*
3) *Little contact with doctors, non with consultants. Almost no communication with patient. (Hurley)*
4) *As family we would have liked a doctor to talk to us and explain what was going on. Only had nursing staff to ask. (Mortimer)*
5) *Dad did not understand why he had to stay in hospital so long and frankly, neither do I! Although the actual nurses were helpful to me, they simply did not have the information to provide. (Loddon)*
6) *Not good. One doctor told me one thing and his boss said something else. Was disappointed. (Sonning)*

3.6 Hygeine and hand washing

Once again the graphs indicate a high level of satisfaction and there were many favourable comments including:-

1) *There has been considerable improvement since my last stay in the hospital during the late nineties. (Hunter)*
2) *ICU exceptional (ICU – obviously!)*
3) *Spotless (Jim Shahi)*

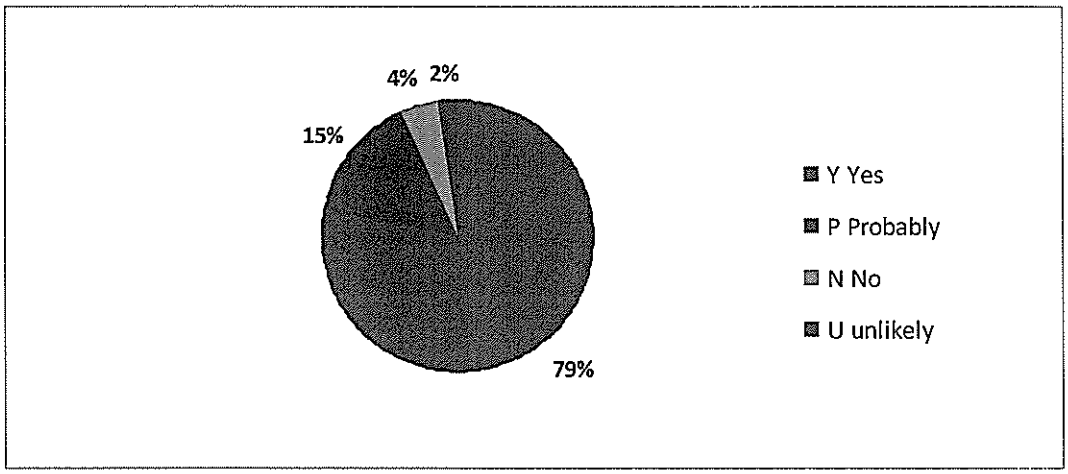


However where there were adverse comments they were frequently of considerable concern

1) *Hand wash excellent. Overcrowded condition meant proper floor cleaning was impossible. (CDU)*
2) *I was put off by a gentleman 'spitting' into the sink just inside ward. Not a nurse, but someone helping on ward. Not English but foreigner. (Jim Shahi)*
3) *Toilets not working properly, no plug in sink, shower not working. (CDU)*
4) ***There was fresh blood on the wall and floor of the toilet on the evening of my arrival. I did not say anything as I wanted to see if it was cleared during its clean in the morning. It was not cleaned and I told a member of staff who dealt with it. Overall the unit seemed to be extremely cluttered and unkempt with many trip hazards. As for hand washing, I wouldn't know – I certainly never saw it and there was no hand gel at my bed. (CDU)***
5) ***I didn't see staff washing their hands, my mother didn't have her hair washed for three weeks. I had to do it, her hair were dirty and uncut. (Stroke unit)***

3.7 Recommendation

In answer to the question about whether or not they would recommend the RBH to a friend on the basis of their experiences, the majority (79%) said Yes and 15% said Probably Yes. Only 6% said No or Unlikely.



This, we believe, is a similar response to that obtained from internal RBH patient experience monitoring. A number of patients who had one or more criticisms of the hospital were prepared to answer this question in the affirmative though one must be aware that the scoring of the question that the Department of Health is proposing to ask will ignore the "probably" votes and will deduct the No and Unlikely votes from the Yes votes to give a hospital score and on this basis the RBH would score 73%.
Ref https://www.wp.dh.gov.uk/publications/files/2013/02/Friends-and-Family-Test-Publication-Guidance-v2-FOR-PUBLIC%E2%80%A6.pdf

There were of course a number of favourable responses to this question :

1) *The Royal Berks is a super hospital and would recommend to anyone.*
2) *As a retired physio assistant, I was very pleased with everything.*
3) *The overall experience was very acceptable. Good care, nice clean hospital and excellent parking.*
4) *Fantastic treatment and excellent nursing and caring. Will never worry about all operations again.*
5) *I really have nothing but praise for all the staff, from porters to consultants. Only 1 or 2 didn't quite reach the same high level as the rest. Taken overall - an excellent hospital.*
6) *I have stayed and visited people in private hospitals in the past, this NHS hospital would put any of them to shame. I would strongly recommend. From the moment of arriving until the moment I left every member of staff were very helpful, caring and most importantly cared about everyone with a big smile on there face.*
7) *Would have to find a fault but I cannot. Very well done everybody. Carry on the good work. Lucky to have the RBH.*

And a few adverse ones :

8) ***Patient was discharged to WBCH for rehab with perforated bowel (symptoms evident for 2 days). WBCH refused admission. On return to RBH patient was taken to theatre for emergency surgery. Some RBH staff have no aptitude for nursing. Some have English which is almost incomprehensible. In my view the care was bodged. It could have resulted in her death and I shall be making a formal complaint.***
9) *Old cleaning equipment, dusty floors, mop and bucket style*
10) ***When I had been on the ward the 16 days prior, I had no concerns and would recommend the RBH. However, the CDU was appalling. I was surprised at how bad it was as, on a tour of the ward in the past, everything was perfect! Enough healthcare assistants to help feed our elderly and the Unit was clean and tidy. It was not an unannounced tour and I can only assume that all stops were pulled out. Such a shame as they have done themselves no favours.***
11) *No wouldn't recommend it to anyone.*
12) *If I need to be in hospital any time, I've said I refuse to go in Woodley ward and Mortimer ward.*

4 Discussion

The response rate of just 19% was disappointing particularly as a significant proportion of those that did respond were day patients. There was a relatively low number of responses from elderly care wards and none at all from Burghfield. However it is acknowledged that this was the first occasion that the RBH has co-operated with a LINk in an independent survey of this type and the managers and staff should be congratulated for their willingness to submit themselves to scrutiny.

The graphs indicate that the majority of patients are complimentary about most aspects of care at the RBH but there are exceptions with weekend and night care and hospital administration attracting a number of poor to average ratings

There are a small number of really quite disturbing reports that have been highlighted n bold type. (3.2 Adverse comments 6 and 7 for both days and nights/weekends) The reported behaviour of agency staff is completely unacceptable and undesirable staff should be reported and blacklisted. Frail elderly people that can eat should be encouraged to eat and catering staff should be charged with ensuring that they can actually reach the food provided. Where food is untouched or barely touched this must be recorded. These are hopefully isolated incidents but they are happening and they need to be eradicated.

It is dangerous to jump to conclusions on the basis of what is still a relatively small sample set but it must be underlined that it is the personal testimonies that are more powerful than the graphs of satisfaction levels. Patient satisfaction may well be up in the 90% levels and above but it is the personal stories that highlight potential dangers ahead.

If we were forced to indicate areas for further investigation then, apart from the wards where one or less questionnaires were returned, there are some grounds to look more closely at Mortimer ward, the CDU and possibly Hurley ward.