

# **WE ARE MACMILLAN. CANCER SUPPORT**

**Macmillan Cancer Support and Yorkshire Cancer Network**

## **Researching Inequalities in Cancer Black & Minority Ethnic Communities and People with Learning Disabilities**

### **End of Project Report People with a Learning Disability December 2012**

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**Yorkshire Cancer Network**

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## **1.) Executive Summary**

The purpose of the project was to Research Inequalities in Cancer for Black & Minority Ethnic Communities and People with Learning Disabilities; there are two separate reports, one for each arm of the project. This purpose of this arm of the project was to gather in depth feedback from people with a learning disability regarding their experiences of using health services and in particular cancer services. The 18 Month project was funded by Macmillan Cancer Support and managed by the Yorkshire Cancer Network (YCN).

The project ran for 18 months, beginning in June 2011 with the employment of a YCN/ Macmillan Learning Disabilities Inequalities Outreach Worker to run a series of focus groups and one to one interviews. The focus groups and interviews would provide a rich vein of feedback from LD groups and individuals about their experiences of using cancer services and health services in general. The findings would then be fed back to service providers with recommendations for any necessary improvements

The major findings highlight the importance of collecting better data around learning disabilities. Collection rates in the UK are poor despite some recent improvements.

We would encourage you to read the full report however, the following are the main recommendations we urge all providers of cancer services to consider when organising and delivering cancer services to people with a learning disability.

### **Recommendation 1:**

**All hospitals within the YCN area should set up a flagging/coding system for admitting people with learning disabilities which will enable statistics on their pathways of care to be generated. In this way hospitals will be able to monitor the local health characteristics of people with learning disabilities, including cancer incidence, mortality etc., and in turn contribute to creating much needed national statistics.**

### **Recommendation 2:**

**All healthcare and social services/independent provider service staff should receive training on helicobacter pylori and the measures which can be taken to prevent infection.**

### **Recommendation 3:**

**The Government should continue GP Health Checks for people with learning disabilities. They should also collect data about the effectiveness of these checks in uncovering previously unidentified instances of unmet health needs so that their effectiveness can be gauged.**

### **Recommendation 4:**

**All areas within the YCN should work towards achieving a minimum of 75% uptake (a level of performance which could reasonably be considered a minimum standard) of GP Health Checks amongst the adults with learning disabilities they support.**

#### **Recommendation 5:**

Local screening teams across the YCN area should liaise to share good practice and ensure that all screening sites are aware of the needs of people with learning disabilities. Reasonable Adjustments to their services should be made to ensure inclusion and equality of accessibility for all.

#### **Recommendation 6:**

No one should be 'ceased' from screening lists if they are deemed not to have capacity to make this decision for themselves unless a Best Interests Meeting has been held.

#### **Recommendation 7:**

All healthcare and social services/independent provider service staffs should have training to ensure they are aware of the Mental Capacity Act and how to apply it in practice. Similarly, staff awareness of Independent Mental Capacity Advocate's (IMCA's), how to contact them and their role should be improved.

#### **Recommendation 8:**

A programme of awareness sessions about cancer, cancer screening and the early signs and symptoms to be aware of should be run for both people with learning disabilities and families and carers across the YCN area.

#### **Recommendation 9:**

National guidelines should be produced for health/social care staff on how to support individuals to self-check for signs of cancer and on how to approach checking for those who are unable to do so for themselves.

#### **Recommendation 10:**

Patients should be able to exit appointments where they are told they have got cancer into a separate area from the general waiting area.

#### **Recommendation 11:**

That Recommendation 1 of the independent inquiry Healthcare for All is upheld and training in learning disabilities offered as part of postgraduate clinical training. Also, that people with learning disabilities and their carers should be involved in developing and delivering this training.

#### **Recommendation 12:**

Health care staff who have already completed their training should attend awareness sessions about making reasonable adjustments for people with learning disabilities. This training should include suggestions about what they can do to make sure that people with learning disabilities have the same access to health care as anyone else. Doctor's surgeries, health centres, hospitals and hospices should sign up to Mencap's Getting it right charter.

#### **Recommendation 13:**

Hospitals should ensure that all patients are assigned a key worker irrespective of how they have been admitted for treatment. Hospital A&E admission pathways should be checked to ensure that key worker assignment is included as part of the pathway.

#### **Recommendation 14:**

All hospitals in the YCN area should have an Acute Hospital Liaison Nurse in post to facilitate reasonable adjustments to ensure equality of access, information and treatment for people with learning disabilities.

**Recommendation 15:**

Information on the availability of benefits, availability of complementary therapies and support groups etc. should be given to all cancer patients in the information pack they are given at their first/'bad news' appointment.

**Recommendation 16:**

All patients with learning disabilities should be offered counselling, preferably with counsellors from Specialist Learning Disability Health Teams, in view of their potentially greater need for support in understanding and coping with their diagnosis of cancer.

**Recommendation 17:**

All patients with learning disabilities should be offered breast reconstruction following mastectomy to ensure they are treated in the same way as any other patient. Assumptions about the suitability of offering this procedure to individuals should not be made based upon the patient having a learning disability.

**Recommendation 18:**

Hospitals should review their cancer pathways to assess what can be done to improve the end of treatment experience of patients so that they do not feel so abandoned.

**Recommendation 19:**

Providers to ensure the appropriate use of tools available to help communication with people with a learning disability such as the ones described on [page 45](#)

**Recommendation 20:**

Some accessible information and details of where to find more should be available everywhere that offers medical treatment or advice. Health staff should be aware of what is available and have copies of that information to give to patients at appointments or be able to write an information prescription for that information to be given to them at an Information Centre.

**Recommendation 21:**

In light of Recommendation 18, an Information Prescription should be written for people with learning disabilities on the cancer pathway.

**Recommendation 22:**

All those who deliver cancer services or support people with learning disabilities to access those services or healthcare in general should evaluate the services they provide to people with learning disabilities in respect of cancer awareness, prevention, diagnosis and care. Further, they should undertake to make a plan of action as to how they can implement some of the recommendations in this report within their area to improve the experience of cancer services for people with learning disabilities.

## 2.) Introduction

The Yorkshire Cancer Network has a strong history of gathering the views of cancer service users through a variety of methods. The user partnership group (UPG) has been keen to ensure that the views of everybody affected by cancer are fed in to service development and improvement but are also aware that this does not always happen, especially with some marginalised groups.

The [Cancer Reform Strategy 2007](#)<sup>1</sup> acknowledges the links between race and cancer and talks about how they are complex and varied across different ethnic minority groups. People from ethnic minorities are generally diagnosed later, less likely to take part in clinical trials and are less likely to access palliative care services.

Further, patient experience data has shown that BME patients generally report worse experiences of cancer treatment and care. Patient experience also shows that people with learning disabilities may have poor access to services when they have cancer symptoms, that they are at a higher risk of developing some cancers and that there is evidence of a low uptake of screening amongst this group. The Strategy also notes that consideration should be given to user involvement from people who may not usually join groups or attend meetings but have valuable experiences of services to share.

The User Partnership Group of the Yorkshire Cancer Network recognised these challenges and was aware that the Cancer Network itself it has not engaged with either of these communities previously. This project was conceived in recognition of the Networks wish to broaden its engagement with patients from ethnic minorities and with learning disabilities across the YCN area.

The User Partnership Group (under the umbrella of the Yorkshire Cancer Network) secured funding from Macmillan Cancer Support to use an outreach research model to canvas the views of people from BME backgrounds and people with learning disabilities on their experiences of accessing and using cancer services in the YCN area. This report is a summary of the achievements of this project and the recommendations the UPG is making based upon these findings.

The project ran for 18 months, beginning in June 2011 with the employment of the Macmillan Learning Disabilities Inequalities Outreach Worker. A consensus was reached to outsource the BME arm of the project, and INVOLVE Yorkshire and the Humber was subsequently commissioned to deliver this part of the project. A project steering group was established with membership from Macmillan Cancer Support and the YCN and included a variety of relevant stakeholders with interest in these two areas. It soon became apparent that a separate reference group for each arm of the project would be useful, with a combined steering group meeting less regularly and so specialist learning disability and BME groups were established encouraging all steering group members to attend either or both groups as appropriate.

The National Cancer Action Team briefing paper Briefing Paper on Practical Action to Reduce Inequalities in Cancer Care<sup>2</sup> includes practical steps that Cancer Networks could take in supporting the NHS Commissioning Board and Clinical

Commissioning Groups to reduce inequalities in cancer care. This project will support the Yorkshire Cancer Network to respond to some of the challenges outlined in the paper.

### **Who should read this report?**

This research and the recommendations contained in it are aimed most specifically at healthcare professionals, clinicians, commissioners and policy makers. However, inequalities in cancer care are issues that should be understood and tackled by all of us. We hope therefore that this report reaches a wide audience – including individuals, managers, patient groups, voluntary and community sector organisations, advocacy and self-help groups.

### **Understanding this Report**

This report is about experiences. The action research programme was designed to find out more about the experiences of patients in their cancer journey – it is not a clinical report and the research team are not clinicians. It looks specifically at the experience of patients, families and carers experiences of cancer care and the impact on their lives. The research is based on conversations with patients, families, carers and professionals and our conclusions are based upon these experiences.

### **Acknowledgements**

We would like to thank all those we have engaged with us throughout the course of this project for their contributions of significant expertise, experience and insight into making this report possible. Without the contributions of these people and their willingness to share their experiences openly and honestly this project would not have been possible. We would also like to thank the members of the Yorkshire Cancer Network's User Partnership Group (particularly the Equality and Diversity Steering Group) for their oversight and management of the project.

# **This Report Concentrates on the Feedback Gained from People with Learning Disabilities, Their Carers and Professionals from Health and Social Care.**

## **Aims and Objectives**

1. To gain an understanding of the cancer services offered, ascertain any gaps in service and assess the access to those services for those with a learning disability and a diagnosis of cancer in the Yorkshire area
2. To capture the experience of patients with learning disabilities and their carers/family who are accessing cancer services
3. To develop an outreach model to ascertain the views of people with learning disabilities regarding their experiences of accessing and using cancer services
4. To make recommendations about robust mechanisms for gaining patient experiences and collecting feedback from service users
5. To share the project data, feedback and subsequent recommendations with relevant health and social care organisations to contribute to reducing inequalities in cancer care services

## **3.) Methodology**

The report's findings are based upon a variety of engagement exercises which included individual interviews, focus groups and speaking with self-advocacy and carers groups.

### **Individual Patient Interviews.**

In total 9 interviews were conducted with patients and their families or carers between November 2011 and August 2012. This input has been greatly valued as everyone involved has given their time freely to share their first-hand experiences of cancer services, stating that they hoped by doing so they would help other people in similar situations in the future. Interviews were held informally but adhered to an interview schedule and all responses recorded anonymously to protect patient confidentiality.

### **Outline of Patient Interview Statistics:**

**9 x interviews – were conducted**

**6 x Female with Breast cancer (3 x Harrogate, 1 x Leeds, 1 x Bradford, 1 x Huddersfield)**

**1 x Female with Lymphoma (Huddersfield)**

**1 x Male with Kidney cancer (Huddersfield)**

**1 x Male with Bowel cancer (Leeds)**



## **4.) What We Found Out**

### **Main Findings:**

**70% have had a GP Health Check - 30% had a liaison nurse or similar available in the hospital they attended - 80% had a key worker assigned - 30% of patients were offered complementary therapies - 40% offered counselling**

**4 out of the 6 patients with breast cancer had mastectomies. 2 out of these 4, or 50%, did not have reconstruction mentioned to them.**

**None of the patients interviewed received appointment invitations in an accessible format.**

**Only one patient received any information on their cancer in easy-read.**

### **Screening:**

**2 people were male**

**Bowel – 1 person was too young; 1 person did not get an invite**

**7 people were female**

**Breast – 4 women were in the correct age group and were invited, 3 women were too young. 100% of those eligible were invited and did attend.**

**Cervical – 2 women went for screening; 3 women did not receive screening invite; 1 woman tried but screening was not carried out due to stress; 1 woman tried but decided to opt out for future appointments. Out of 7 patients with a learning disability 4 were invited for cervical screening but only 2 completed the screening successfully; 3 out of 7 were not invited.**

### **Staff Interviews**

Interviews were conducted with a wide range of professionals representing generic and specialist learning disability health services, social services and the private learning disability service sector. Those interviewed included Lead Cancer Nurses, Clinical Nurse Specialists, Health Facilitators, Matrons, Learning Disability Community Nurses, Screening Service Providers, Cancer User Partnership Group Facilitators, Information Leads and Carers/Support Workers. Again, overwhelming support for the project and improving service inequalities was expressed by all those interviewed. Each interview was informal and did not follow an interview schedule thus allowing questions to be adapted to the position held by the individual concerned and for conversations to flow freely.

### **Focus Groups.**

Two focus groups were held. The first was devised as a piece of joint working between health and social services which involved a collaboration between the Macmillan/YCN Project Worker, a Senior Commissioning Manager for Learning Disabilities Services from North Yorkshire and York PCT, the Service Development Manager for Learning Disabilities from North Yorkshire County Council and the Chief Executive of Inclusion North (who promote inclusion for people with learning disabilities, their families and carers). The meeting was entitled 'Working Together for Better Health' to which staff from support providers for people with learning disabilities were invited. Representatives from 18 services attended and the notes from this focus group, including all questions asked, are available in [Appendix I](#).

The second focus group was conducted as part of the Self-Advocates' Forum for the, Learning Disabilities Partnership, North Yorkshire. 29 people with learning disabilities were in attendance and were asked questions about what the word cancer made them think/feel, what they knew and would like to know about cancer and screening programmes, whether they had been for a GP Health Check and what format for accessible information they preferred.

### **Speaking with Self-Advocacy Groups.**

We talked with 3 self-advocacy groups:

Roots – group for African, African Caribbean and dual-heritage people (Leeds)

Bradford People First Healthy Living Group

Talkback Consulting Group (Harrogate)

Roots – self-advocacy group for African Caribbean or dual-heritage people with LD:

No members had been invited to have GP Health Checks.

Bradford People First Healthy Living Group:

60% have had a GP Health Check.

Talkback Consulting Group:

50% of members have had a GP Health Check.

Accessible information - in general feedback from all 3 groups was:

most people prefer easy-read information and to see photos or drawings to illustrate the text. Video presentation was the most popular way to receive information.

Voice recordings and braille were also advocated, especially by those with sight impairments.

Being told if a relative or friend has cancer (ref. Macmillan report 'Supporting people with learning disabilities who are affected by a friend or relative with cancer', 2011):

91% said they would want to know.

### **Improving Health and Lives: Learning Disabilities Observatory.**

Throughout this report reference is made to the Improving Health and Lives: Learning Disabilities Observatory (IHAL). This organisation was set up in 2010 by the Department of Health in response to recommendation 5 in Healthcare for All (Michael, 2008)<sup>3</sup>, the report of the independent inquiry into access to healthcare for people with learning disabilities:

'To raise awareness in the health service to the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.' P.10

IHAL's objective is to provide knowledge and information aimed at enabling health and social care agencies to improve the health and well-being of people with learning disabilities in England.

## **'A working definition of Learning Disabilities'**

In its first publication A working definition of Learning Disabilities (IHAL, 2010)<sup>4</sup> states that the current definition of learning disability can be taken from 'Valuing People: A New Strategy for Learning Disability in the 21<sup>st</sup> Century' (DH, 2001)<sup>5</sup>:

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development. (p.14)

## **5. Some Facts and Figures**

### **Numbers of People with Learning Disabilities.**

#### **National Figures**

There is no definitive record of how many people there are with learning disabilities in England but the most recent data from IHAL (People with Learning Disabilities in England 2011<sup>6</sup>) estimates that there are 1,191,000 in total, comprising 286,000 children (0-17 years) and 905,000 adults (18+) which equates to roughly 2.25% of the population (population of England = 53,013,000, 2011 census<sup>7</sup>).

#### **Local Figures**

In 2004 the Department of Health commissioned Emerson and Hatton at Lancaster University to produce robust estimates of current and future numbers of people with learning disabilities in England. The report<sup>8</sup> stated that specialist services will mainly be aware of those with severe learning disabilities and therefore the majority of people, who have less severe learning disabilities but may still have significant support needs, are likely to not be known to those services. Using known data sets on learning disability numbers and administrative prevalence statistics they were able to calculate the likely prevalence of people with learning disabilities in England.

Based upon this research IHAL have created a table showing the expected numbers of people with a learning disability in each local authority area. See

<http://www.improvinghealthandlives.org.uk/numbers/howmany/laestimates/index.php?region=D&area=00DB> for full national data, accessed 15/11/12.

Below is data for the area covered by YCN (fig.1).

Area	Population	Number Probably Known to Services	True Likely Number	Likely Number as % of Total Population
Bradford	506,800	2,325	10,070	
Calderdale	201,600	916	4,021	
Kirklees	406,800	1,864	8,147	
Leeds	787,700	3,697	16,315	
North Yorkshire	579,700 (N.B. does not show Harrogate & Craven)	2,666	11,977	

	separately)			
Wakefield	323,900	1,476	6,522	
York	198,700	919	4,103	
Totals	3,005,200	13,863 (0.46%)	61,155	2.04%

The most recent Joint Strategic Needs Assessment (JSNA) for each area within the YCN region provides local statistics for general and, in some areas, learning disability populations. These reports show the population of Harrogate as 158,700 and Craven as 55,400, a total of 214,100. [Appendix II](#) shows these figures (fig. 2) with links to the full reports.

## Growing Numbers of People with Learning Disabilities

Studies such as Healthcare for All (2008)<sup>3</sup> reveal that the prevalence of people with learning disabilities in the general population of the UK is expected to increase by approximately 1% per year for the next 10 years leading to a 10% growth by 2020. Improvements in maternal and neonatal care plus improvements in general health care for those with learning disabilities means that it is expected that there will be an increase in the complexity of disabilities. For the same reasons the life expectancy of people with learning disabilities is increasing every year. As the risk of developing cancer increases with age it is therefore likely that the incidence of cancer will also rise for this population group.

## Data Issues

One of the main problems faced by researchers seeking to analyse the experience of healthcare by those with learning disabilities in England is that it is not possible to gather accurate data on acute episodes of care due to the lack or inconsistent use of coding for learning disability in hospitals.

Healthcare for All (2008)<sup>3</sup> observes:

‘People with learning disabilities are not visible or identifiable to health services, and hence the quality of their care is impossible to assess. Data and information on this subset of the population and their journeys through the general healthcare system is largely lacking and what exists is inadequately co-ordinated or understood.’ (p.8)  
This absence of identification also means that, if hospital staff are not aware that someone has a learning disability, they will not make any necessary adjustments to the way care is offered to ensure that the patient can benefit as much as anyone else from the services provided. This is called making ‘reasonable adjustments’.

Healthcare for All further observes that this lack of identification means that:

‘it is difficult for services to prepare properly or make the necessary ‘reasonable adjustments’ if patients’ communication and other special needs are unknown. Mistakes can lead to failures of treatment, risks for the patient, and a failure to engage other partners, including carers, in the treatment plan.’ ( p.36).

The report goes on to make the recommendation that:

‘All health care organisations including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.’(Recommendation 2, p.37)

Despite this clear recommendation from the independent inquiry data is still not widely collected on people with learning disabilities accessing acute care.

IHAL is taking up this issue and has recently published a paper about it entitled 'Have you got a learning disability?' (2012)<sup>9</sup>, which addresses lack of data collection as a national, and indeed international, problem. It observes that whilst coding systems for learning disability do currently exist, they are outdated and not applied with any consistency. IHAL therefore make recommendations on how these coding systems should be changed to meet current needs and that they are adopted into all areas of NHS information systems.

Within the YCN area two Trusts have developed flagging systems as part of their admissions procedures to alert hospital staff that the patient being admitted has a learning disability.

### **Mid Yorkshire Hospitals NHS Trust Flagging System**

The Patient Administration System (PAS) used by acute providers in this area contains an alert flag for identifying people with learning disabilities. Upon admission the PAS computer screen flashes red "learning Disabilities" indicating that the patient being admitted has a learning disability. The ward clerk or nurse fills in a Patient with Learning Disabilities form at this point and sends it to the Safeguarding Office located in Trust HQ. There it is picked up by the area's Acute Hospital Liaison Nurse (ALN) who provides a link between hospital services, the patient and community. The ALN is then able to liaise with the departments involved to facilitate any adjustments necessary to ensure that the patient has an equitable experience of care.

This identification of learning disability upon admission is facilitated by a number of systems links generated within the Mid Yorkshire area. These include proactive recording of patient details on PAS when the registration forms for both Health Action Plans and VIP (Vulnerable In-Patient) cards are completed and links between the Annual Health Check registers for locality GPs and PAS.

To cover any out-of-office-hours admissions, the Night Matron's report for new admissions is reviewed and any new admissions requiring a flag are entered onto PAS.

**For further information please contact:**

**Marie Gibb, Strategic Health Facilitator,**

**Pinderfields Hospital, Mid Yorkshire Hospitals NHS Trust**

**Marie.Gibb@midyorks.nhs.uk**

### **Calderdale and Huddersfield NHS Foundation Trust Flagging System**

Calderdale and Huddersfield NHS Foundation Trust worked with NHS Kirklees and NHS Calderdale to utilise the GP DES registers to put an alert on the internal PAS (Patient Administration System) of all known patients with a learning disability. This allows an email alert to the Matron so she can provide support to individual patients and carers, and reasonable adjustments can be highlighted. This was done in accordance with Information Governance, Information Security and the Caldicott Guardian.

**See 'Reasonable Adjustments' p.30 for details of VIP (Vulnerable In-Patient) Hospital Passport for people with learning disabilities from the same Trust.**

### **Admissions**

Although it is generally not possible to generate statistics on admissions of people with learning disabilities with a cancer diagnosis, we have managed to gather some data covering admissions for the last 3 years from the Calderdale and Huddersfield NHS Foundation Trust area. These figures come from the area's Matron Complex Needs Care Co-ordinator who, like Acute Liaison Nurses, provides a link between patients and acute services.

#### **Cancer Admissions and Outcomes.**

##### **Amanda McKie, Matron Complex Needs Care Co-ordinator, Calderdale and Huddersfield NHS Foundation Trust.**

Amanda's role means that she is alerted to any admissions of people with learning disabilities at both Calderdale and Huddersfield Hospitals and, like an acute liaison nurse, she is therefore aware of all episodes of cancer care for people with learning disabilities within the trust. Amanda was able to revisit her case notes for the past 3 years to produce the following statistics.

- 20 patients with cancer were diagnosed over the last 3 years (2009-2012).
- 12 male; 8 female.
- Cancers diagnosed: 3 bladder; 2 cervical; 2 bowel; 2 breast; 2 oesophageal; 1 multiple lymphoma; 1 brain tumour; 1 stomach; 1 prostate; 1 lung; 1 low rectal; 1 colon; 1 testicular, 1 multiple myeloma.
- 7 GP referrals and 13 A&E admissions.
- 8 treatable cancers and 12 palliative.
- 9 patients deceased within 1 year, most much sooner; 1 deceased within 18 months.

The presence of a full-time specialist Matron within the hospitals means that reasonable adjustments are consistently made. These include: regular use of best interests meetings, 1:1 support from a learning disability nurse, use of accessible information, first appointments on theatre lists, use of a side room on wards, good multi-disciplinary liaison, familiarisation visits to wards prior to treatment and treatment units and parents being allowed to accompany a patient to theatre.

As can be seen from the data on the previous page, 65% of admissions were acute/via Accident and Emergency. Of course, this data is representative of only one of the seven trust areas covered by YCN. However, it is nonetheless worrying. When compared with the statistics gathered by IHAL (2012)<sup>6</sup> for all non-psychiatric admissions to general hospitals for adults with learning disabilities, a disquieting picture emerges. IHAL indicates that in the Yorkshire and The Humber region 49% of all admissions in the year 2008-9 happened as emergencies (p.19). Nationally the emergency hospital admission figures are 50.0% of all admissions for people with learning disabilities versus 31.1% for those who do not have learning disabilities (IHAL, 2012<sup>6</sup>, p. 18). This finding is significant as it reveals that emergency admissions are substantially higher for people with learning disabilities. Acute admission often involves greater suffering and poorer outcomes for the patient. It also means that advance planning is less possible which is especially important for this group of patients as it means reasonable adjustments are unlikely to have been planned in anticipation.

### **Recommendation 1:**

**All hospitals within the YCN area should set up a flagging/coding system for admitting people with learning disabilities which will enable statistics on their pathways of care to be generated. In this way hospitals will be able to monitor the local health characteristics of people with learning disabilities, including cancer incidence, mortality etc., and in turn contribute to creating much needed national statistics.**



## **Known inequalities in access to healthcare and consequent treatment for people with learning disabilities.**

People with a learning disability are 58 times more likely to die before the age of 50 than the general population and 4 times more likely to have a preventable cause of death (McGuigan et al., 1995)<sup>10</sup>.

People with learning disabilities are 2.5 times more likely to have health problems than other people (Disability Rights Commission, 2006)<sup>11</sup>.

One in seven adults with learning disabilities rates their general health as 'not good' (Emerson and Hatton, 2008)<sup>12</sup>.

In recent years there have been many national reports published on the inequalities in healthcare experienced by people with learning disabilities. There can be many reasons for people with learning disabilities finding health services difficult to access. These range from a lack of reasonable adjustments enabling access, to a lack of awareness of learning disabilities amongst staff and 'diagnostic overshadowing', where symptoms of physical illness are mistaken for behaviours associated with an individual's learning disability and therefore not investigated or treated.

It is well known that poorer health is experienced by those who are socially isolated, unemployed, living in poverty and/or poor housing. People with learning disabilities are more likely to experience some or all of these factors. They are also less likely to have good awareness of their bodies or healthcare needs.

A significant number of people with learning disabilities have a communication style which other people find it difficult to understand. For this reason it can be difficult for them to express pain or discomfort in ways which are recognised by carers and healthcare staff. Those who know the individual well such as family members or long-term care staff are in the best position to identify changes in behaviour which could suggest ill health or worsening conditions and yet reports such as Mencap's *Death by indifference: 74 deaths and counting (2012)*<sup>13</sup> suggest that their opinions are frequently ignored.

## **Cancer Incidence in People with Learning Disabilities.**

No recent statistics for cancer incidence and mortality for people with learning disabilities have been compiled but some data is available. These show that the proportion of people with learning disabilities who die from cancer in the UK is lower than for the general population – 12-18% versus 26% but the incidence of gastrointestinal cancer is proportionately much higher for this group – 48-59% versus 25% of cancer deaths (Jancar, 1991<sup>14</sup>; Cooke, 1997<sup>15</sup>; and Duff et al. 2001<sup>16</sup>). Further studies have found that, compared with the general population, there is an increased risk of childhood leukaemia for individuals with Down's syndrome and a lower risk of solid tumours, including breast cancer (Hasle et al., 2000<sup>17</sup> and Hermon et al., 2001<sup>18</sup>).

A recent study of the attitudes of nursing staff in UK general hospitals found that they were less likely to have positive feelings towards people with learning disabilities than those with physical disabilities (Lewis and Stenfert-Kroese, 2010<sup>19</sup>).



Also people with learning disabilities who have cancer have been found to be less likely to be informed of their diagnosis or prognosis, less likely to be given pain relief, less involved with decisions about their care and less likely to receive palliative care (Tuffrey-Wijne et al., 2007<sup>20</sup>; Bernal, 2008<sup>21</sup>; Tuffrey-Wijne et al., 2010<sup>22</sup>).

The class 1 carcinogen helicobacter pylori which is linked to stomach cancers, gastric ulcers and lymphoma has been shown to be very common in people with learning disabilities (Hogg and Tuffrey-Wijne, 2009<sup>23</sup>). A study of psychiatric inpatient units for people with learning disabilities in 2008 (Clarke et al.<sup>24</sup>) conducted antibody tests for helicobacter pylori on all residents the outcome of which indicated that 59% of them were infected. Greater awareness of this bacterium and the simple preventative measures which can be taken to avoid infection such as improvements in hand hygiene could have a huge impact on its prevalence.

Cancer Research UK states that the age standardised (which provides unbiased comparisons between different populations, with respect to age) rate of cancer incidence is roughly 0.4% of the population. On this basis it would be expected, using JSNA totals in fig.2 (Appendix 1), that 103 people with learning disabilities would be diagnosed with cancer in the YCN area annually. If we use IHAL's figures for 'True Likely Numbers' as seen in fig.1 (p.5), this number increases to 214\*.

\*Figure adjusted to take account of the YCN area covering only Harrogate and Craven in the North Yorkshire area (37% of total for North Yorkshire), the separate population statistics for which can be seen in Appendix 1 (fig. 2).

### **Recommendation 2:**

**All healthcare and social services/independent provider service staff should receive training on helicobacter pylori and the measures which can be taken to prevent infection.**

### **GP Health Checks**

Health checks are routine checks (a form of screening) for ill health or health risk. Primary health services have a legal responsibility (under the Disability Discrimination Acts 1995, 2005 and the Equality Act 2010<sup>25-27</sup>) to take account of the special needs of people with learning disabilities and reduce the health inequalities they face. GP practices in England can address this by offering annual health checks. Since 2009, GPs have received extra money for providing health checks – about £100 for each check carried out as part of a Directed Enhanced Service (DES). This DES is currently in place until March 2013. The standard format for these checks is called the Cardiff Health Check which follows a tick box format with yes/no answers in response to a series of questions on the individual's health. Several of the staff from different areas within YCN however told us that they have found this model unwieldy so they have developed their own local versions. Currently GPs do not have to report on the effectiveness of these checks in identifying new cases of unmet health need.

IHAL statistics for the year 2011-2012<sup>28</sup> show that 53% of people with learning disabilities eligible for a health check in England were given one. The YCN area PCTs generally show better statistics:

Wakefield District PCT – 60%; Kirklees PCT – 69%; Calderdale PCT – 71%;

Bradford and Airedale Teaching PCT – 72%; Leeds PCT – 58%

However, North Yorkshire and York statistics currently only show that 31% of all adults eligible for an annual health check are receiving one across the area. It should be noted that this is a very rural area so uptake can be more difficult to facilitate.

Results of engagement from interviews focus groups, self-advocacy groups and professionals:

All interviewees stated that they found their GP's surgeries and appointment booking systems accessible.

7 out of 10 or 70% of those interviewed have had a GP Health Check.

The support worker for one interviewee said that she felt GPs and Practice Nurses should listen to carers more when health checks are done as they are likely know the person with learning disabilities well and therefore be able to input meaningful insights to examinations/investigations.

#### **An interviewee's experience of GP Health Checks in relation to her later diagnosis of cancer:**

The interviewee was invited for her first health check in April 2011 at the age of 29. Her mother and aunt have both had breast cancer and so her doctor had advised that she should have regular breast area MRI scans from the age of 30 as a precautionary measure. Therefore her GP notes should have reflected this area of concern. The interviewee felt that the nurse who conducted the health check did not go through the whole list of points to cover during the check and no explanation of this was given. At no time during the health check was breast checking or cancer mentioned. It would thus appear that GP notes were not consulted prior to or in conjunction with the health check.

The interviewee had been advised to practice self-checking of her breasts due to the family history of cancer. In August 2011, whilst undertaking one of these checks, she discovered a lump in her breast. Her GP acted quickly and she was referred for tests which were conducted within 2 weeks. These showed that she had breast cancer. She has since had successful treatment, including a mastectomy and is making a good recovery. However, the interviewee and her family strongly believe that if her breasts had been checked earlier in the year at her health check then the lump may have been detected sooner increasing potential survival chances.

For further information on GP Health Checks for people with learning disabilities see the IHAL report Health Checks for People with Learning Disabilities: A Systematic Review of Evidence (2010)<sup>29</sup>.

### **GP Surgery 'Mystery Shopper' Exercise in Bradford.**

Bradford People First Healthy Living Group have carried out a series of 'Mystery Shopper' visits to GP practices in Bradford to find out about how they support people with learning disabilities and whether or not they are offering Annual Health Checks.

Self-advocate members of the Healthy Living Group called all of the GP practice managers in Bradford to see how good their communication with the person with a learning disability was and what services they provided. They then sent out a questionnaire about Annual Health Checks and the support they give people with learning disabilities. 84 questionnaires were sent out and 31 returned. The survey found that most surgeries remind people about Annual health Checks but that whilst just under 2/3 of surgeries who responded had their accessibility to health checks rated as either 'good' or 'ok' by the self-advocates, just over 1/3 were rated 'could be better' or 'could be a lot better'. Over half of the surgeries who replied had some information in an easy-read format. Three quarters of those who responded said 'yes' they would like some help from the healthy Living Group to make their surgeries more accessible to people with learning disabilities.

The group are contacting these surgeries to make plans for helping them to be more accessible and the results of this survey will be fed back to NHS Commissioners by the Healthier Lives Sub-Group in Bradford.

**For further details please contact:  
Bradford People First Healthy Living Group,  
[healthyliving@bradfordpeoplefirst.org.uk](mailto:healthyliving@bradfordpeoplefirst.org.uk)**

### **Recommendation 3:**

The Government should continue GP Health Checks for people with learning disabilities. They should also collect data about the effectiveness of these checks in uncovering previously unidentified instances of unmet health needs so that their effectiveness can be gauged.

### **Recommendation 4:**

All areas within the YCN should work towards achieving a minimum of 75% uptake (a level of performance which could reasonably be considered a minimum standard) of these health checks amongst the adults with learning disabilities they support.

## Screening Services

It has been found that people with learning disabilities have reduced access to generic preventative screening and health promotion procedures, such as breast or cervical screening. Recent research by Truesdale-Kennedy, Taggart and McIlfatrick (2011)<sup>30</sup> has particularly highlighted deficiencies in breast cancer screening for women with a learning disability. Data from Davies, N. & Duff, M. (2001)<sup>31</sup> suggested that women with learning disabilities are far less likely to attend breast screening than the general population. This can be due to a number of factors such as a perception either by themselves or those who support them that the process is painful, too stressful or inaccessible for those with certain physical disabilities.

A support worker who works at a group home has told us that staff have tried cervical screening with each of the women residents without success and so they have decided against pursuing it.

Further results of engagement from interviews focus groups, self-advocacy groups and professionals:

One interviewee told us that when she was recalled for a second breast screening appointment she was not told that this would include having a biopsy taken and having that procedure done without warning was distressing for her. Her carers would very much have liked to have been made aware that the biopsy was a possible part of the appointment so that they could have prepared her for what would happen and thus avoid extra unnecessary stress.

Only one of the 10 patients interviewed was over 60. This gentleman was 68 and should therefore have been sent a testing kit for bowel cancer. However, this had not happened.

Service providers attending the joint health and social care focus group told us that, for people who were in the age range for each cancer screening in each of the 18 support services represented:

61% of the services supported breast screening.

58% of the services supported cervical screening.

40% of the services supported bowel screening.

If these statistics are placed alongside the 75% acceptable level of eligible population generally expected to attend screening, we can see there is some shortfall. Staff from the service providers at the focus group told us that none of the invitations received for screening appointments or instructions sent with bowel screening kits were in an accessible/easy-read format.

Lloyd (2010)<sup>32</sup> states in *Access to Healthcare for People with Learning Disabilities*:

'Female patients with LD were significantly less likely to have received contraceptive advice than those in the matched patient population. This may be for one of three reasons (amongst others) (i) patients with LD may be assumed not to be sexually active, (ii) patients with LD may be assumed to be incompetent of making choices regarding contraception, (iii) GPs may be reluctant to raise the issue of contraception with patients with LD. A further study, looking at sexually transmitted infection, pregnancy and termination rates amongst the LD population may be advisable.

Similar reasons may explain why female patients with LD were significantly less likely to have a record of smear tests than those in the matched patient population. In addition, GPs may fear frightening patients, and may consider that conducting a smear test would be practically difficult for a patient with LD.' p.10

Screening teams throughout the country have been working hard to dispel these worries and IHAL have recently published a report<sup>33</sup> on the ways that different organisations have improved awareness of and access to services. Included in this report are two local case studies, the authors of which are very happy to share their aims and outcomes. These examples of good practice are reproduced below.

### **A pilot to increase uptake of cervical screening in Wakefield**

The results of a health equity profile undertaken in Wakefield showed that over the last 5 years 14% of women without a learning disability were ceased from Cervical Screening Register compared to 47% of women with learning disabilities. Women with a learning disability aged 25-40 were almost 5 times more likely to be ceased from the programme or be placed in an exceptions category.

In response to these findings, the local strategic health facilitator and public health commissioning manager developed a pilot programme to look into this matter further. They decided to use the Open Exeter system to examine the cervical screening histories of women with learning disabilities. This system was used to identify women who are up to date with cervical screening, identify women who have been ceased from the recall system and identify women where cervical screening has been successful in the past but is now overdue.

The pilot plans to look at approximately 60 women who have a learning disability and are between 24-64 years of age. These women have had a cervical screen in the past but are now overdue.

The proposal to undertake this work has been reviewed by a clinical governance lead and the Cancer Screening Co-ordinator for Wakefield to ensure that it adheres to the Caldicott principles surrounding the sharing of patient identifiable information.

The purpose of this pilot is to identify and reduce physical and organisational barriers and improve access to cervical screening for women with learning disabilities in Wakefield. It is also intended to provide guidance for support workers, general practice and decision makers in order to increase screening uptake.

10 women whom we support have consented to be involved in this pilot and are being supported through their screening journey.

**For further information please contact:**

**Karen Gillott**

**[karen.gillott@choicessupport.org.uk](mailto:karen.gillott@choicessupport.org.uk)**

### **Improving uptake of breast screening in the Pennine area.**

In the Pennine area, the Breast Screening Department worked with the Strategic Health Facilitator from Bradford District Care Trust, to discuss access to the breast screening programme for women with learning disabilities and assess current uptake. Information on women with learning disabilities aged 50-70 in the Bradford and Airedale area was obtained from the Learning Disability Register. Using the woman's NHS number, the information was cross-checked with records on the National Breast Screening Service to assess attendance. 201 women aged 50-70 were on the Learning Disability Register. The information gathered showed a high percentage of women recorded as DNAs (Did Not Attend) and cancelled/opted out. Although some reasonable adjustments were already in place, a review of current practice identified the need for better communication with women with learning disabilities including an easy read invitation letter, and the need to increase the knowledge and confidence of carers to support women to attend breast screening/take care of their breasts.

In response to the needs identified, an easy read screening invitation letter was developed in partnership with the self-advocacy group Bradford People First, and a training package was developed for carers and supporters of women with learning disabilities. The course aimed to increase awareness of breast screening and breast health and explore ways of supporting women with learning disabilities. The course has run twice and has evaluated positively.

#### **For further information please contact:**

**Lynn Clark,  
Health Promotion Specialist,  
Pennine Breast Screening, St. Luke's Hospital, Bradford.  
lynn.clark@bthft.nhs.uk**

**Bowel Cancer UK** has launched a new resource for people with learning disabilities to help them and their carers to make informed choices about bowel health and screening programmes. Although the information is specifically about the Scottish bowel screening programme, it contains useful generic information and advice and will hopefully prompt a similar publication being developed for the rest of the UK. Aimed at individuals aged 50-74, information on The Bowel Health and Screening Pack is available from <http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/>



**Informed Choice about Cancer Screening** has undertaken consultation with the public, experts and opinion leaders on the information sent to people invited for screening. Feedback was gathered between January and September 2012 and the results are now available on-line at: <http://www.informedchoiceaboutcancerscreening.org/>

The feedback gathered will be used to revise the proposed approach to offering information on screening and these will be published on the website shortly. Responses to the consultation indicate that people want to be made aware of the risks as well as the benefits of screening so that they can make an informed choice about whether or not to participate. Interestingly, people generally showed a preference for information to be given to them using the combination of plain English text with pictures used to illustrate it.

- 85% of people wanted the benefits and harms of cancer screening information to be presented in pictures AND words
- 85% of people preferred a simplified non-technical description of cancer screening rather than a detailed scientific description.
- 78% of people would prefer the pictures used to be photos with 14% preferring drawn images.

### **The Mental Capacity Act 2005 and Consent.**

Individuals are required to give informed consent prior to testing for all screening programmes. If an individual is considered to not have capacity to give their own consent a meeting, known as a Best Interests Meeting, should be held. This meeting should include information from relevant professionals, family members and the person who lacks capacity. If these people do not attend the meeting their views must be represented. At the meeting a decision is made as to whether or not it is in the individual's best interests to be screened. If this meeting decides screening is not in the person's best interests they can then be removed from the screening list, a process known as 'ceasing'.

The Mental Capacity Act 2005<sup>34</sup> is underpinned by five key principles to be considered when assessing capacity:

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Interviews with specialist learning disability health staff have revealed two known cases of individuals 'ceased' from screening lists without Best Interests Meetings. Both cases involved cervical screening.

In the first case a GP decided that screening was not applicable to the patient and so removed them from the list themselves.

In the second case a family asked the GP to remove their family member from the list as they felt it would be distressing for them to undergo the screening procedure. The individual was removed from the list by their GP without wider consultation.

Anyone who lacks capacity to consent to major decisions, and who does not have someone to support or represent them in a Best Interests Meeting, must be referred to an Independent Mental Capacity Advocate (IMCA). Similarly, if the decision made by a Best Interests Meeting is disputed, an IMCA should be consulted to give an independent opinion. In all the interviews undertaken within the project only one instance of using an IMCA was related. The experience of the healthcare staff involved was that it held up the process of treatment to an unsatisfactory extent and delays in consultation meant that, in their opinion, the outcomes of treatment were not as good as they might have been if treatment could have started sooner. There was a general consensus amongst staff (healthcare, carers and social services) that IMCAs are a resource about which there is little knowledge and therefore use of their services is limited. This was especially the case amongst healthcare staff.

#### **Recommendation 5:**

**Local screening teams across the YCN area should liaise to share good practice and ensure that all screening sites are aware of the needs of people with learning disabilities.**

**Reasonable adjustments to their services should be made to ensure inclusion and equality of accessibility for all.**

#### **Recommendation 6:**

**No one should be 'ceased' from screening lists if they are deemed not to have capacity to make this decision for themselves unless a Best Interests Meeting has been held.**

#### **Recommendation 7:**

**All healthcare and social services/independent provider service staffs should have training to ensure they are aware of the Mental Capacity Act and how to apply it in practice. Similarly, staff awareness of IMCAs, how to contact them and their role should be improved.**

The next section is a summary of the findings from the interviews and focus groups held throughout the project. The section is divided into segments which broadly follow the cancer care pathway.



## Awareness and Early Diagnosis

The self-advocates we spoke with during the project had all heard about cancer, saying that it made them feel 'panic', 'scared' and 'upset'. They also observed that although it was a subject some felt they 'could not talk about in the past' they could do so more now and despite thinking that they 'hope it doesn't happen to me' they acknowledge that it 'does not happen to everyone' and 'not everyone dies'. All the self-advocates had some further knowledge about cancer but they wanted to know more, especially about the signs and symptoms of cancer to be aware of.

Good outcomes for cancer treatment are heavily influenced by peoples' awareness of cancer and effective early diagnosis by health care staff. For people with learning disabilities awareness and early diagnosis can be improve via increasing the uptake of GP Health Checks and Screening Services and a growth in awareness of the signs and symptoms of cancer and the need for self-checking in both people with learning disabilities and families/carers.

One of the barriers to effective early diagnosis we heard about from health care professionals we spoke with was diagnostic overshadowing. Healthcare for All, 2008<sup>3</sup> states:

'Diagnostic overshadowing is the term used by the DRC (Disability Rights Commission) and others to describe the tendency to attribute symptoms and behaviour associated with illness to the learning disability, and for illness to be overlooked. Witnesses reported that the phenomenon is widespread, and is particularly problematic in palliative care or when someone with a learning disability is in pain and can only communicate distress through behaviour (such as screaming or biting) that staff find challenging and/or difficult to interpret. The Inquiry heard many examples of this most disturbing problem and is very concerned that it should be addressed urgently. (p.18)

This inquiry further describes diagnostic overshadowing as:

'the term used to describe the impact of ignorance coupled with negative attitudes at the interface between staff and their learning disabled patients, .... Education and training in these issues for staff is severely limited. Staff without training tend to stereotype people with learning disabilities; they are less likely to listen, or to believe that a life lived with learning disability could be a life worth living.' (p.54)

Provider services staff at the Focus Group 'Working Together for Better Health' told us that the barriers they experienced to supporting good health included: - 'Lack of staff continuity when supporting appointments' - 'Lack of continuity of staff at GPs' - 'Staff presuming issues relating to age or condition rather than a health problem. Not investigating further' - 'Lack of knowledge re learning disability and syndromes in GPs generally' - 'Lack of awareness of learning disability and communication aids' (in health staff)

Some useful tools we are aware of for use by carers to aid early recognition of illness include the Disability Distress Awareness Tool known as DisDAT and the Anticipatory Care Calendar.

### **Recommendation 8:**

**A programme of awareness sessions about cancer, cancer screening and the early signs and symptoms to be aware of should be run for both people with learning disabilities and families and carers across the YCN area.**

## Self-Checking

### Background and potential barriers

It is recognised that individual self-checking is an important component of awareness and early diagnosis initiatives. This can, however, be a difficult area to approach when faced with concerns such as the individual's ability to check themselves effectively, the sensitive issue for staff of physical touch and the lack of staff training and guidance in this area. Current consensus appears to be that staff should carry out visual checks only. This is however of limited use, as by the time there are visual signs a potential cancer may already be advanced.

### Results of engagement

Our interviews with staff from regional Learning Disability Health Teams and Support Service Providers have revealed that health and support workers would like more guidance on self-checking for people with learning disabilities. They recognise that this is an important component of awareness and early diagnosis but, due to the barriers to physical touch, especially in areas such as the breast or testicles, many staffs are concerned about how to approach this initiative in a safe manner.

Similarly, feedback from the workshops held with self-advocates has shown that individuals are concerned about cancer and would like to know how to self-check and what signs and symptoms they should look out for to detect possible early signs of cancer.

At the 'Working Together for Better Health' focus group 3 of the 18 services represented said that they support people to self-check – only 1 in every 6 services.

**Breast Cancer Care** offers information and support for anyone affected by breast cancer. Their Breast Health Promotion team provide breast awareness training, which includes information on self-checking, and can be delivered to people with learning disabilities. . It also offers a 1 day course in working with people with Learning Disabilities designed to support trainees in delivering the breast awareness message to women with mild to moderate learning disabilities.

#### Contact details:

The Breast Health Promotion team

Breast Cancer Care

Phone: 0845 092 0809

Email: [bhp@breastcancercare.org.uk](mailto:bhp@breastcancercare.org.uk)

Website: [www.breastcancercare.org.uk/breast-awareness](http://www.breastcancercare.org.uk/breast-awareness)

Breast Cancer Care also publishes 'Supporting people with learning disabilities to take care of their breasts', a resource designed to help people with learning disabilities be breast aware, with the support of their carer.

This can be ordered, free of charge from:

<http://www2.breastcancercare.org.uk/publications/breast-health/your-breasts-your-health-supporting-people-learning-disabilities-bcc163>

Two Projects from other areas of the country have linked up to address the issues around self-checking and cancer screening, case study below.

### **The Josephine Project**

The Josephine Project works with women with learning disabilities and is run by Them Wifies, a community arts organisation based in Newcastle-upon-Tyne. Josephine is an anatomically correct “larger than life” cloth person and a creative learning resource. Through the use of drama, role playing and interactive group activities the project works with women with learning disabilities to promote awareness around vital health and relationship issues.

The Josephine course offers a 10 week programme focussed on Josephine and her journey as she looks at a range of important issues such as dating, personal safety and choice, safe sex and contraception and any other subjects related to sex and relationships that women wish to look at during the course.

#### Contact Details:

T: 0191 261 4090

E: [enquiries@themwifies.org.uk](mailto:enquiries@themwifies.org.uk)

W: <http://www.themwifies.org.uk/projects.html>

### **Choice Support work with the Josephine Project**

In November 2009 Choice Support, a social care charity providing support services for disabled and disadvantaged people, based in London, commissioned Them Wifies to deliver four days training and workshops about Health Checks in Stockport, Milton Keynes and London. Over 50 women attended the training with Them Wifies. The feedback was very positive and as a result Choice Support decided to sign a license agreement with Them Wifies purchasing Choice’s own Josephine, training and resource packs for a team of trainers to deliver Josephine workshops to Choice Support service users. Five of these trainers are women with a learning disability. Whether women have capacity or not they are invited to attend workshops which use drama to explore sensitive issues like self-checking and screening. Since the introduction of the Josephine Project Choice Support has seen a significant increase in the number of eligible woman accessing breast screening.

Self-checking for testicular cancer raises similar issues to checking for breast cancer.

Easy read resources on self-checking are available from the CHANGE Cancer Series of books, the Books Beyond Words Series and Fair Multimedia. Details in the list of resources,

### **Recommendation 9:**

**National guidelines should be produced for health/social care staff on how to support individuals to self-check for signs of cancer and on how to approach checking for those who are unable to do so for themselves.**

## Diagnosis and Treatment

As discussed on page 5, under Data Issues, it is well reported that it is not possible to gather accurate data on acute episodes of care due to the absence of coding for learning disability in hospitals. For this reason we have concentrated on gathering qualitative testimonies detailing perceptions and direct experience of cancer.

### Diagnosis.

We asked all interviewees 'What does the word 'cancer' mean to you?' the following are representative of the feedback received:

- 'Cancer is asleep in your body and I thought 'Oh, it's woken up!'
- 'I might die.'
- 'I was worried that I would be right poorly'.

We also asked self-advocates what they thought/felt when they heard the word 'cancer', responses included:

- 'Scary'
- 'Frightened'
- 'Might get better'
- 'Panic'
- 'Hope it doesn't happen to me'
- 'Not everyone dies'

Generally speaking, the self-advocates we spoke with had some knowledge about cancer but this was mainly of a general nature. Some words such as 'Chemotherapy' and 'radiotherapy' were known but their meaning was not fully understood.

All the patients interviewed had some level of understanding of what had happened to them with about half having a very good appreciation of their diagnosis

One interviewee told us that it would have been really beneficial to have had the opportunity to pre-book a familiarisation visit to the Bexley Wing in Leeds before their first appointment as it is such a big site. They also suggested that it would be useful if there was the facility to book hospital appointments and complementary therapy appointments to coincide with each other to economise on lengthy and costly journeys.

### **Helping both patient and staff cope with a breast cancer diagnosis.**

All but one interviewee had been told by a consultant that they had cancer following diagnostic tests. The individual who was not told of the negative results directly was judged by support staff to need extra help in understanding what was happening and so staff arranged with the hospital for a nurse to come to the patient's home to help explain everything to her. The nurse brought along a breast prosthesis and a bra and worked with the support worker to prepare the patient for what was to come. Working in this individualised way reportedly helped the patient's comprehension and an acceptance that she was poorly and would need treatment. The support worker observed that the diagnosis was also a very difficult time for the staff that supported this individual at her home. All were saddened and some were very worried about what a mastectomy would look like and how they would react to it when giving personal care. The lead support worker asked the nurse who visited to show the patient pictures of a mastectomy to help prepare her for what was going to happen and how she would look post-surgery. Similarly this support worker prepared staff at the home by finding examples of mastectomies on the internet and organising a special information session for staff so that they could ask questions and be prepared for supporting the patient through her treatment.

### **Interviewee suggestions:**

- One interviewee, a patient's Mum, felt that wearing a Macmillan badge does not always instil confidence. She said that this was because at the appointment where they were to get the results of the tests on her daughter's breast lump the consultant was accompanied by a Breast Care Nurse who was wearing a Macmillan badge. This immediately established a tension that the results were not going to be positive before they had been told the results, which the mother found very distressing.
- After the 'bad news' appointment, a very distressed patient and carer had to walk out into the main waiting area. They strongly felt that being able to go out of a different door into a quiet area and having a separate room available in which to sit and take everything in would have made a difference. That experience added to their distress and, they felt, must also have added to that of the other patients waiting for their appointments who they felt must have been upset by their distress and worried for the outcome of their own appointments.

## **Recommendation 10:**

**Patients should be able to exit first or 'bad news' appointments into a separate area from the general waiting area.**

Some themes were mentioned again and again: learning disability awareness, reasonable adjustments, the type of information supplied, Key Workers, Acute Hospital Liaison Nurses, information on the benefits/complementary therapies available, counselling, breast reconstruction and how people felt at the end of their treatment. Each of these areas is therefore examined below.

### **Learning Disability Awareness**

Several patients expressed the feeling that awareness about learning disabilities was low.

One interviewee said 'some people were a bit sharp' (in their tone) and seemed 'nervous' 'as if they weren't sure how to talk to me' - not seeming to know how much she could understand.

Another told us she 'felt that staff awareness was better 'when someone has somebody with a learning disability in their family.'

Other feedback received:

'I think there should be training about learning disabilities given to more people, especially in hospitals.'

'Staff tried very hard but I felt that perhaps they hadn't had learning disability training.'

The studies conducted by the independent inquiry Healthcare for All (2008)<sup>3</sup> found that:

'Witnesses giving evidence to the Inquiry agreed that there are serious shortcomings in education and training for staff. Work with people with learning disabilities per se is not a compulsory part of training, other than clinical psychology pre-registration training. 'Diagnostic overshadowing' ..... may occur in relation to other groups (such as older people, people with mental health problems), but witnesses speaking to the Inquiry argued that learning disability, in many ways, represents a special case. This is largely because of the ignorance that still surrounds learning disability. There is a strong argument, for this reason, in favour of including basic teaching about learning disabilities in all pre-registration courses and involving people with learning disabilities in providing it.'(p. 34)

The report goes on to make the recommendation that:

'Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.'(Recommendation 1, p.36)

### **Learning Disability Awareness Training Available Across the YCN Area.**

Some training in learning disabilities is available within the YCN area. The following are some examples our interviews with healthcare staff have revealed.

Huddersfield Royal Infirmary and Calderdale Royal Hospital both have induction leaflets on learning disabilities for new starters. Existing staff also have Learning Disability Awareness Training available to them but this is not mandatory. Learning Disability Champions exist in both hospitals.

Bradford Hospitals also have Learning Disability Awareness Training available to them, delivered by nursing staff from the Specialist Community Learning Disability Health Team. This training is also not mandatory and uptake by hospital staff can be low.

In Mid Yorkshire there are currently about 95 learning disabilities champions in hospitals across Wakefield, Pontefract and Kirklees. Anyone from a porter to a chief executive can be a champion. The aim is for there to be one Learning Disability Champion for each ward/department in Mid Yorkshire area hospitals. In order to become a champion the individual needs the backing of their line manager and to attend a one full day Learning Disabilities Awareness session at Fieldhead Hospital in Wakefield. On this course the content covers: national and local perspectives, Mencap's *Death by indifference* (2009)<sup>34</sup>, the roles within the Community Team for Learning Disabilities, communication behaviours, family/carer involvement and a service user with learning disabilities delivers a presentation entitled 'It's My Life'. Champions meet bi-annually as a network of trainees. Previous focus of meetings has included: seeing beyond a disability and communication with an emphasis on Makaton. They always try to have a keynote speaker and someone from one of the hospital departments delivering a case study from their experience.

Healthcare for All (2008)<sup>3</sup>:

'Sometimes.....treatment is not offered to people with a learning disability because a judgement, albeit an inaccurate one, is made about its value. Such judgements imply that a life lived with learning disability is a life less valued.'(p.18)

'Staff without training tend to stereotype people with learning disabilities'. (p.54)

#### Case Study from Patient Interview

**It was discovered that one interviewee carries a gene which makes reoccurrence of her cancer and potential spread much more likely. A consultant recommended a double mastectomy and removal of her ovaries as a precautionary measure. At this point, and after an otherwise pleasant consultation, he said words to the effect of – 'and so you won't be able to have children but that won't be an issue for you'. The patient and her mother were shocked and surprised that such an assumption should be made, and so casually stated without embarrassment, apparently based upon the patient's learning**



### **Recommendation 11:**

**That Recommendation 1 of the independent inquiry Healthcare for All is upheld and training in learning disabilities offered as part of postgraduate clinical training. Also, that people with learning disabilities and their carers should be involved in developing and delivering this training.**

### **Reasonable Adjustments.**

#### **Feedback from interviewees on appointment times.**

We asked people: 'Were you offered the option of a first or last appointment?'

Most people said that this had not been offered.

We then asked: 'Would this have been useful to you?'

There was a mixed response to this, varying from the person not being sure or saying 'Not really' to a definite 'Yes' and one carer commenting that it would have been useful 'especially as we are also carers of another person with learning disabilities' and this would have meant 'less waiting for everyone'.

We also asked: 'Were you offered an appointment that was longer than the usual length of time?'

Again, most people said that this had not been offered.

We then asked: 'Would this have been useful and why?'

We received some responses indicating that it would 'not really' have been necessary but more indicating that this would have been very useful, especially to make sure that the process of giving and receiving of information was given the time it needed. Responses included: 'Yes. More time to talk about things' and 'More time to make sure everything was understood.'

Interviewees said that although they were not offered either of the above reasonable adjustments they felt they had not needed them either as their understanding of what was happening was good or because they always felt that they had been given as much time as they needed in the appointments they had and had never been made to feel rushed.

Generally speaking, most people we interviewed reported that the hospital staff they came into contact with were really helpful and some of this positive feedback is recorded in the section 'What was good about your experience?' on p.41 of this report. The following are some of the helpful reasonable adjustments made by staff which have been reported to us by interviewees:

- One carer being allowed to accompany the patient with a learning disability to the anaesthetist's area before their operation.
- A carer and also, in a separate episode of care, a mother being able to stay with the patient with a learning disability overnight in hospital.
- Space being made in a Chemotherapy suite for a carer to sit with the person she cares for whilst the person received treatment.



### **Staff feedback on reasonable adjustments.**

The following are examples of the types of reasonable adjustments staff have told us about during the project. We have listed these in order to show the breadth of assistance which can be offered to patients, especially where a Hospital Liaison Nurse post is in place.

Reasonable adjustments facilitated by the Matron, Complex Needs Care Co-ordinator covering Huddersfield Infirmary and Calderdale Royal Hospital (covers Hospital Liaison Nurse function):

- The Matron created an individualised visual book using images from the standard colorectal pack given to one gentleman and accompanied him home to ensure that his and his carers' understanding of what was happening was further explained and understood.
- Chemotherapy for one patient was arranged at a set time on a set day and mainly with the same nurse so it was as predictable and therefore felt as 'safe' as possible.
- Pre-admission familiarity tours of the hospitals are organised for patients for whom it would be useful.
- Equally, the Matron arranged a pre-treatment familiarisation visit to the radiotherapy unit at Leeds and to the Chemotherapy unit at the Macmillan Centre in Calderdale Royal Hospital for a patient and her mum. Both Radiotherapy and Chemotherapy were arranged to be predictable for the patient – Chemotherapy being offered on the same day and time slot with no waiting times and radiotherapy given at the same time on each consecutive day.
- The Matron is able to be present at most hospital appointments to help with any issues regarding communication/understanding information and to advise both patients and staff.
- A communication toolkit is available for any patients admitted to Huddersfield Royal Infirmary with a learning disability to support communication.
- Similarly, a VIP (Vulnerable In-patient) Hospital Passport is available which details important information about the patient in an easy-read format. See case study below for further details.
- A Support Nurse from the local area Specialist Community learning Disabilities Health Team can be organised to assist the patient and their Support Workers as necessary.
- One patient was given a TV guide and free access to television for some of his stay as this was judged to be an important part of helping him to feel more comfortable (the TV guide is important to him at home) and therefore less anxious.
- Learning Disability Champions exist in a variety of areas within both hospitals.
- On admission one patient was found to be very anxious about noise and attending hospitals and had difficulty in understanding what was happening. Best Interests meetings were therefore held to establish the reasonable adjustments which could be made. As a result the patient was offered a quiet side room and his understanding supported by use of pictures and a communication toolkit.
- The Matron was able to organise an overnight stay for two nights for patient's mum so that she could stay with her daughter when she was admitted for surgery. The Matron also met the family at the hospital at 7.30am and stayed all day to be available for facilitating 'reasonable adjustments' and helping with asking/answering questions.
- The only patients we interviewed during our project who received any easy-read information were given it by this Matron.

- Excellent liaison between the hospitals, the local Community Learning Disability Health Team, social workers and the patients' home can be facilitated as needed for all cases.

Reasonable adjustments facilitated by Clinical Nurse Specialists at Bradford Royal Infirmary:

- Pre-admission familiarisation visits to wards.
- Special arrangements for items to be brought from home to make hospital stay more comfortable e.g. a patient's radio.
- CNS conducted a pre-admission home visit to gain a better understanding of the needs of the patient to be admitted.

### **VIP Hospital Passports**

These easy-read documents detail important information about the patient such as advice on how best to give medical interventions such as injections or x-rays, allergy advice, personal care needs and the means of communication used by the patient. The passport is designed to be kept by the patient's bedside to be easily accessible for hospital staff to consult as and when necessary.



**For more information please contact:**

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Example passport available at:

[http://www.cht.nhs.uk/uploads/tx\\_tspagefileshortcut/VIP\\_hospital\\_passport.pdf](http://www.cht.nhs.uk/uploads/tx_tspagefileshortcut/VIP_hospital_passport.pdf)

### **Mencap's 'Getting it right charter':**

Mencap has worked with healthcare professionals and Royal Colleges to develop this charter which spells out nine key activities which healthcare professionals should implement to ensure that there is equal access to health services for all people with a learning disability.

Mencap ask that healthcare organisations sign up to the charter and implement its recommendations by making reasonable adjustments where necessary. The aim is to create momentum for change via effective collaboration across all healthcare services.

This pledge and guidance on implementing it can be found at:

<http://www.mencap.org.uk/sites/default/files/documents/2010-06/charter.pdf>

### **Recommendation 12:**

**Health care staff who have already completed their training should attend awareness sessions about making reasonable adjustments for people with learning disabilities. This training should include suggestions about what they can do to make sure that people with learning disabilities have the same access to health care as anyone else. Doctor's surgeries, health centres, hospitals and hospices should sign up to Mencap's Getting it right charter.**

### **Interviewee Suggestions:**

- Nutritional advice would be useful during treatment 'in order to feel you are doing the best you can to give yourself the best chance.'
- Currently wigs given to patients experiencing hair loss are renewed every 6 months. One patient's experience is that they wear out after 3 months wear so she would have liked to be able to have a new wig every 3 Months.

### **Key Workers**

All but one of the patients were given a key worker whom they could contact with any questions throughout their cancer journey. All patients who were assigned a key worker found it very reassuring to know they were there if they had any queries and were contacted at some point by over half of the patients interviewed who 'rang to discuss worries' and 'found this very helpful'. The patient who was not assigned a key worker was admitted via Accident and Emergency and, although follow up appointments post-surgery were in the Bexley Wing at St. James' Hospital in Leeds, they did not see a Clinical Nurse Specialist at any point during their treatment as all appointments were with a consultant only. The support staff member who was also interviewed stated that it staff would very much have liked to have had a key worker as they felt there had been a lot of unanswered questions throughout the treatment journey. When queries had arisen staff had waited until seeing a doctor on a ward round, at a scheduled appointment or had made an appointment to see their GP to ask them. The facility to ring someone direct would have saved a great deal of time and, on occasion, uncertainty and worry.

### **Recommendation 13:**

**Hospitals should ensure that all patients are assigned a key worker irrespective of how they have been admitted for treatment. Hospital A&E admission pathways should be checked to ensure that key worker assignment is included as part of the pathway.**

#### **Acute Hospital Liaison Nurses**

This role, usually held by a specialist learning disability nurse, provides a link between hospital staff and services and people with learning disabilities, their parents and/or carers. Our conversations with healthcare staff found that this role is usually held by one person but may be covered by a combination of staff where a single dedicated role does not exist.

Mencap's 'Death by *Indifference*' (2007)<sup>35</sup>:

'the ability of acute hospitals to provide a consistently good service to people with a learning disability continues to be an area of concern, particularly for those with the most complex needs' (p.32).

In order to address this inconsistency, staff need to be conscious of the nature and importance of making reasonable adjustments for people with learning disabilities and have an awareness of consent and capacity issues ensuring the use of best interests meetings. Whilst Disability Awareness Training is under attended the best way to address inequalities is to have a specialist learning disability nurse in a dedicated post in hospitals. This need was recognised by the independent report by Sir Jonathan Michael 'Healthcare for All' (2008)<sup>3</sup> which states:

'Best practice and the views of witnesses suggest that the most effective partnerships across service boundaries are forged when someone in the locality takes clear responsibility for their development.'

And

'The Inquiry believes there would be value in strengthening the workforce resource in general in this area through a Directed Enhanced Service incorporating health checks and general health liaison provided by acute liaison nurses.' (p. 42)

This proposal was subsequently taken further in 'Death by *Indifference* – 74 Deaths and counting' (Mencap, 2012)<sup>13</sup> which recommends that:

'acute learning disability liaison nurses are employed by every acute service, and are linked to senior leadership, who have a strategic role in supporting ward staff to make reasonable adjustments' (p.30).

Currently there are 3 people who cover the Acute/ Hospital Liaison Nurses post across the YCN area – one each in Calderdale and Huddersfield, York and Wakefield, with a further post currently being advertised in Leeds. This means that 4 out of the 7 NHS Trusts in the YCN area do not employ an Acute Liaison Nurse or someone in a post with similar responsibility.

Results of engagement from interviews focus groups, self-advocacy groups and professionals::

One patient told us that having a learning disability made it very hard to talk to people and say what her feelings were. She suffered from shyness and, as she lives on her own, did not have the support of a carer. For her, the support of someone in the hospital

who understood her needs and advocated for her when she could not do so for herself would have made a huge difference to her experience of treatment and managing her fears.

Only 30% of interviewees had an Acute Liaison Nurse or similar available in the hospital they attended.

All patients interviewed who did not have an Acute Liaison Nurse available at the hospital they attended said that the presence of someone in this role would have been extremely useful and reassuring to them.

'If someone was there who could understand better (experience of treatment) it would have been fine.'

'Yes, definitely!', 'Yes, it certainly would!' (have been useful to have an Acute Hospital Liaison Nurse available).

The presence of an Acute Liaison Nurse not only provides support for reasonable adjustments to be made within hospitals (evidence of which can be seen on pp. 27-28 of this report) but can also result in improved resources being available physically within those hospitals and also on-line. Good examples of this within the YCN area are the Calderdale and Huddersfield NHS Foundation Trust and the Mid Yorkshire Hospitals NHS Trust websites. Both sites have a dedicated learning disabilities page with links to useful documents in easy-read format and also links to other local learning disabilities pages at local council sites such as Learning Disability Partnership Boards.

#### **One Patient's Experience of Radiotherapy:**

One of the patients we spoke with said that she felt she had not been properly prepared for the fact that she would have to have tattoos applied to her skin before having radiotherapy. She found the process very painful and distressing and felt that she had no support after the radiotherapy had finished. She said that she would very much have 'liked to have someone to talk to to see what other people have experienced.'

The presence of an Acute Hospital Liaison Nurse at the hospital could have ensured that help was given to this patient to understand what was going to happen to her and that she was offered the post procedure support she needed, thereby significantly reducing her distress.

#### **Case Study: Evaluation of the Learning Disability Acute Liaison Nurse Post in Wakefield.**

Local NHS spending cuts threatened the much valued post and so an evaluation was carried out. The report contains the outcomes of an Equality Impact Assessment, details of how the post supports delivery of the Strategic Objectives and QIPP programme, a breakdown of Finance and Resource Implications (including efficiency/financial gains arising from ALN intervention, productivity and value for money), implications for Risk Management and a summary of the role and responsibilities of the post.

The report proved successful and further funding for the post was secured.

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### **Recommendation 14:**

**All hospitals in the YCN area should have an Acute Hospital Liaison Nurse in post to facilitate reasonable adjustments to ensure equality of access, information and treatment for people with learning disabilities.**

### **Awareness of benefits, support groups and the complementary therapies available.**

Patient interviews revealed that they were given very little information on the benefits available.

‘It isn’t well advertised that travelling costs can be claimed including parking’ – It ‘would be good to be advertised in the initial St. James’ Hospital (Leeds) information pack – Macmillan information about free prescriptions is included in initial pack.’

‘Would have been useful to have more information, especially about benefits’.

Was told about free hospital parking ‘at second visit’ - ‘Would have been good to have been told at first appointment’.

None of the patients interviewed had accessed cancer support groups but one interviewee had an excellent experience of using The Haven Breast Cancer Support Centre in Leeds and The Robert Ogden Macmillan Centre. Another interviewee and her carers living in Bradford reported that the social workers they dealt with ‘had no idea about what support was available.’ They had, however, received excellent 1:1 support from the organiser of local breast cancer self-support group Bosom Friends (Bradford).

They had been given a bar of soap promoting Bosom Friends by their hospital in relation to possibly attending a fashion show the group were staging to raise funds. However, no mention was made by the hospital at the time that the group could be a good source of information and support. The patient and carer contacted Bosom Friends and since then the group have been their main source of information and advice on available support such as the complementary therapies available at the Robert Ogden Centre and benefits such as free parking.

Only 30% of patients interviewed were offered free complementary therapies in their area. Even where therapies are available on the same hospital campus as treatment is given, patients are not always told of their existence. Specifically, two of the patients interviewed who received treatment in the Bexley Wing at St. James’ Hospital in Leeds were not told about the Robert Ogden Macmillan Centre on the same site, or the availability of free complementary therapies there for cancer patients. Giving out this information seems to be inconsistent however, as another patient at the same site reported that they found information about therapies readily available.

The hospital sites at which complementary therapies are available in the YCN area are the Robert Ogden Macmillan Cancer Information and Support Centre (St. James Hospital, Leeds), Cancer Support Bradford and Airedale (Bradford Royal Infirmary) and York Cancer Centre (York Hospital).

Interviewees who had accessed free complementary therapies had done so at the Robert Ogden Macmillan Cancer Centre and The Haven Breast Cancer Support Centre in Leeds. Both centres have reportedly offered the patients an excellent range of therapies and support.

- One interviewee has found attending a specialist yoga class for people with, or who have had, cancer at the Knaresborough Yoga centre has been extremely beneficial. Small class sizes mean sessions can be tailored to the individual and she has met another person with learning disabilities there. The camaraderie which exists within these classes has helped as a coping strategy by making her realise 'you're not alone'. The interviewee observed that she felt that information on locally available support such as this class should have been given to her by her local GP practice rather than having to find out about it herself.

#### **Case Study from Patient Interview.**

##### **Lack of income from social services to support extra care at home and travel to radiotherapy.**

We spoke to one supported living provider about their experiences of supporting a lady with breast cancer. The lady and her housemates usually went out to work placements during the day and so there was no provision for staff to be in attendance at the group home during office hours. Staff told us that once this particular lady had started treatment for her cancer she became very tired and sometimes poorly and so would have liked to have been able to stay at home rather than continue to attend those work placements. The staff reported that they therefore made an application to their local social services team for extra income to enable staff to support this lady at home during the day. This application was turned down.

Similarly, funding to cover staff taking the lady to her course of radiotherapy appointments some distance away was also turned down with the comment being made that she should access the ambulance patient transport service instead. The lady is not able to use transport on her own and staff may not have been able to accompany her on this service. The lady also felt extremely tired and sometimes quite unwell after these treatments and so having to wait for and travel by a public transport service in these circumstances would have been very distressing for her. Staff were very upset about the situation and did not know where else to turn for support.

We put the staff team in contact with the advisors at the Robert Ogden Macmillan Cancer Centre in Leeds and happily they and the lady have received help from Macmillan Cancer Support.

#### **Recommendation 15:**

**Information on the availability of benefits, availability of complementary therapies and support groups etc. should be given to all cancer patients in the information pack they are given at their first/'bad news' appointment.**



## **Counselling**

We asked interviewees 'Do you suffer from emotional challenges associated with your diagnosis of cancer? (E.g. Low mood, depression, anxiety)':

4 patients told us they had suffered with 'low mood'

3 mentioned feeling 'anxious':

'Sometimes I'm anxious – I still break down'.

1 patient said she had suffered panic attacks:

'I felt very poorly and had panic attacks with the chemo. appointments.'

One interviewee was very anxious at the beginning of his treatment, needing to know the dates and times of his appointments and have them regularly repeated to him. A lot of conversation took place between the patient, his carers and the Matron from the hospital to help his understanding and many meetings held, including Best Interests meetings, to ensure that reasonable adjustments were made to help this anxiety.

Another interviewee reported that since her treatment for cancer she still often felt 'upset' and had 'lost some confidence, not seeing friends as much', tending to 'hold feelings inside'. Her carers asked their health centre in Bradford for counselling in November 2011. At the time of the interview in mid April 2012 they had not yet received an appointment due to the oversubscription of the service. The carers initially addressed the issue by organising lots of fun trips but were then told about the Robert Ogden Centre at St. James' Hospital and have since accessed counselling through them to excellent effect.

One carer felt that the person she supported was much changed by her experience 'It altered her'... she is now 'unwilling to look at the wound or touch it' and 'doesn't wash the area when she has a bath now.' She was 'cheeky before' but is now more reserved. No counselling was offered to this patient at any time. On reflection the carer feels that it would have been extremely useful if the patient could have been offered some specialist therapy, such as art therapy, to help her come to terms with her experiences and the physical differences in her body which have resulted.

The 3 interviewees who received counselling did so in the following ways:

1 interviewee had 2 counselling sessions arranged via her GP.

1 interviewee had some sessions via the Bexley Wing at Leeds.

1 interviewee had 4 sessions and her carer who was also very upset had 5 sessions at the Robert Ogden Centre, Leeds.

### **Recommendation 16:**

**All patients with learning disabilities should be offered counselling, preferably with counsellors from Specialist Learning Disability Health Teams, in view of their potentially greater need for support in understanding and coping with their diagnosis of cancer.**



## **Breast Reconstruction**

Our project revealed that 4 out of the 7 patients interviewed who have or have had breast cancer were given mastectomies. 2 out of these 4, or 50%, did not have reconstructive surgery mentioned to them at any time during their treatment.

It is important to note that, as this feedback was received from only two patients no definite conclusions can be drawn. It does however raise the question about potential value judgements being made by healthcare staff as to whether or not reconstruction was appropriate for the patients based upon their learning disability.

### **Recommendation 17:**

**All patients with learning disabilities should be offered breast reconstruction following mastectomy to ensure they are treated in the same way as any other patient. Assumptions about the suitability of offering this procedure to individuals should not be made based upon the patient having a learning disability.**

## **End of Treatment**

Interviewees have told us that they have felt at a loss when their treatment has ended. Two have specifically said they 'felt abandoned'. Although there was an understanding that they had been given a good prognosis, they felt that they were being 'left to get on with it' which, after a busy time with lots of input from healthcare staff, felt very disconcerting. Worries about the future and whether they would become sick again were very present which, although experienced by most cancer patients, is particularly unsettling for people with learning disabilities.

### **Pilot HOPE Course Run by CHANGE and Macmillan Cancer Support.**

The HOPE course is a well-being course for people who have received treatment for cancer. It aims to help people to be involved with planning their own health and well-being, set goals they know they can reach, learn to cope with ups and downs and know when to seek help. CHANGE have worked with Macmillan Cancer Support and Coventry University to develop a version of the course for people with learning disabilities and a pilot course held at CHANGE in Leeds has just been completed. Although only three people attended this pilot course, both attendees and the development teams involved have found it extremely useful.

Running the pilot has helped course facilitators to have a better insight into the experiences and needs of people with learning disabilities who have undergone cancer treatment and will be able to adjust the course content accordingly. It is hoped that the course will be able to run locally again in future and will also be rolled out nationally.

#### **For further information please contact:**

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**or**

**Lisa Cooper,**  
**Macmillan Cancer Support**

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### **Recommendation 18:**

**Hospitals should review their cancer pathways to assess what can be done to improve the end of treatment experience of patients so that they do not feel so abandoned.**

### **End of Life - Hospices and Palliative Care**

- Outline of processes available e.g. Liverpool Care Pathway, Gold Standards Framework (Rosaleen Brawn), Anticipatory Care Calendar (Tracey Keats)
- Hospices had little experience
- Lack of time meant this area not researched
- Good practice existing

As related earlier in this report - people with learning disabilities are less likely to be given pain relief, less involved with decisions about their treatment and less likely to receive palliative care (Tuffrey-Wijne et al., 2007<sup>20</sup>, p.40). Findings from Ahmed et al., 2004<sup>36</sup> (p 41) show that this is especially so if they are also from a minority ethnic group

#### **Resources:**

Just 'B' Bereavement Support, based in Harrogate, North Yorkshire:

[www.justb.org.uk](http://www.justb.org.uk)

Contact details: 01423 856790, [info@justb.org.uk](mailto:info@justb.org.uk)

New model for breaking bad news developed by Irene Tuffrey-Wijne, Chair of the Palliative Care for People with Learning Disabilities Network and her team at St. George's University of London. The model is aimed at giving guidance for practitioners, families and carers on how to support people with learning disabilities in bad news situations (any situation – not just about ill health or bereavement).

[www.breakingbadnews.org](http://www.breakingbadnews.org)

Contact: [info@breakingbadnews.org](mailto:info@breakingbadnews.org)

#### **Easy-Read Syringe Driver Booklet Developed in Staffordshire**

An easy-read booklet for people with learning disabilities about using syringe drivers for pain control during palliative care has been developed by a Palliative and End of Life Care Facilitator in Staffordshire. The current version is for the Graseby MS26 syringe driver but it is hoped that a version for the recently launched the T34 ambulatory pump will be produced early in 2013. To produce the booklet the facilitator worked closely with the learning disability facilitators in her team and, although it has not been used very often she has told us 'when we did it was invaluable'.

**For further information please contact:**

**Jo Kennedy**

**Palliative and End of Life Care Facilitator**

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### **Case Study: Improving end of life care for adults with learning disabilities.**

Nottinghamshire Healthcare Trust and Sherwood Forest Trust have created an end of life care pathway for people with learning disabilities. This pathway helps to raise awareness of their needs as well as giving mainstream professionals greater support. The main aims of the pathway are to ensure that an individual with a learning disability receives improved care at the end of life, to improve joint working and to decrease emergency admissions.

An 'Improving End of Life Care for People with Learning Disabilities Resource Pack' has been developed to sit alongside the pathway and is included in the end of life folder provided to local GP surgeries and care homes. An accessible version of an information prescription has also been produced and a DVD about receiving bad news created in collaboration with local learning disability drama group Make it Happen. A copy of this film is soon to be available online in the Things to do with Health section of the Nottinghamshire Learning Disability Partnership Board website: [www.nottscounty.pb.org](http://www.nottscounty.pb.org) under End of Life Care.

#### **For further information please contact:**

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## **Communication and Information**

Throughout the pathways the issues of communication and information recurred as a barrier to people with learning disabilities either being aware of cancer or accessing early diagnosis and/or treatment for cancer.

### **Communication**

One interviewee reported that staff at the hospital they attended did not seem to realise that she found it difficult to understand questions and information. Once they realised she had a learning disability they were more helpful and provided smiley/sad face symbols for her to use to help her say how she felt. A learning disability flagging system at the hospital could have helped this support being given from the start of her journey.

Another interviewee reported that there were no communication aids such as a Hospital Passport or Hospital Communication Book available at the hospital they attended. She also observed that hospital staff talked over the patient she was supporting, directly to the support staff and talked about the patient rather than to her. The supporter felt that there was very little awareness about learning disabilities in the hospital staff they met and that the patient's

notes on communication contained in her Health Care Plan which accompanied her to the hospital cannot have been properly read as on one visit the supporter was told by a nurse that 'she (the patient) hasn't filled this form in.' The notes clearly stated that the patient does not read or write.

Another carer told us 'I just think it's really important that carers get listened to (by healthcare staff). Often they know more about the person than the family do, especially carers with a lot of experience with the client.'

Many people with learning disabilities communicate in ways that other people find difficult to understand. The many reports written on this subject suggest that this issue affects between 50% and 90% of people with learning disabilities. If a person finds it difficult to express how they feel, make themselves understood or to fully understand what is happening in their own bodies, they are less likely to be able to alert family or support staff to early signs of ill health. The result therefore is likely to be inequality of access to and experience of healthcare. This issue can be an important contributing factor to diagnostic overshadowing, discussed earlier in Awareness and Early Diagnosis, p.20 and have a negative impact on timely diagnoses and treatment outcomes. As can be seen from the statistics collected by the Matron in Calderdale and Huddersfield NHS Foundation Trust (Admissions, p. 9), almost two-thirds of all learning disability cancer admissions during the last 3 years have been via A&E admissions, the outcomes of which were only 8 cancers being treatable whilst 12 have been palliative and 9 patients dying within 1 year, most much sooner.

#### **Measures to aid communication:**

- Use of the Disability Distress Awareness Tool, or DisDAT, to help carers identify distress in people with learning disabilities and thereby potential ill health.
- Use of Hospital Communication Books or Health Passports in hospitals which respectively aid communication and detail an individual's personal communication style. See resources for details of accessing a copy of the Hospital Communication Book.
- Employment of Acute Hospital Liaison Nurses, as discussed earlier.
- Increased uptake of Communication Skills Training for staff –
- Increased awareness and use of Independent Mental Capacity Advisers (IMCAs) see Mental Capacity Act section on pp. 18-9.
- Increased awareness and use of Intensive Interaction, an approach to communication with people who use little or no speech.
- Use of the Anticipatory Care Calendar which uses daily health assessments designed to alert staff to health changes and provide clear directions about accessing primary care.

#### **Recommendation 19:**

**Providers to ensure the appropriate use of tools available to help communication with people with a learning disability such as the ones described above**

## Information

The Department of Health's (DH) Power of Information<sup>37</sup> (2012) information strategy sets out their aim of harnessing information and new technologies to improve care and outcomes for public health, the NHS and social care across England. The Equality Analysis (DH, 2012)<sup>38</sup> which followed this report examines the potential issues which could arise from changing the way information is collected and accessed in England for some sectors of the population. Concerns around confidentiality, consent and information governance are raised and the link between literacy and health outcomes particularly highlighted, especially for those with learning disabilities.

'Low levels of literacy affect many different groups in this country and mean that they do not achieve their best possible health and care outcomes. The average reading age of the UK population is 9 years, 1 in 6 people in the UK struggle with literacy and this means their literacy is below the level expected of an 11 year old. However, there are issues around how to identify who needs easy read information. Only 20% of adults with learning disabilities are known to learning disability services. As a result of this, there is a risk that those with learning difficulties will not benefit from access to information such as medical records to the same degree as the rest of the population.' (p.10)

The Equality Analysis advocates the production of more easy-read/accessible resources and recognises the use of such resources, not just for those with learning disabilities but also for many other groups in society.

'Good quality easy read information and accessible web sites developed for people with learning disabilities will be equally useful to other marginalised groups including: older people, BME communities, Gypsies and Travellers, young people and anyone who finds reading hard. However, accessible information should not be 'labelled' as being for people with learning disabilities as it is likely to not only put off other groups, but people with learning disabilities themselves who do not wish to identify as such.'(p.23)

- Evidence gathered on what's available
- Interview feedback – patients ('overwhelmed', nothing in given at 'bad news' appointments in accessible formats, no appointment letters sent in accessible formats either) and staff (feeling there was more they could do, Macmillan Bus, Information centres)
- Macmillan bus – very helpful staff with good knowledge but very few easy-read materials.
- All interviewees said that more accessible information would have been useful to them.
- Preferred formats: 6 x easy read (two of which preferred photos to drawn images); 5 x video; 3 x 1:1 chat with someone who knows them and their communication needs well.
- Self-Advocate Groups feedback:  
Easy-read information - in general feedback from all the 4 groups was: most people prefer easy-read information to use photos or drawings to help explain the text. The need for more information in audio or braille formats was highlighted for those who are blind or have partial sight.
- DVDs or videos were the most popular way to get information.

- Voice recordings and Braille were also liked, especially by those with sight difficulties.
- Information discovered and note re: resources list in appendices
- Lack of use of Holistic Needs Assessment
- Offering easy-read alongside standard information would mean that patients could make their own choice about which was best for them rather than just having one option (esp. good for those with better reading and comprehension skills). This could also help staff as there would be no embarrassment about making assumptions as to whether an individual has a learning disability or not. Some people for whom English is not their first language may also welcome being offered a more accessible text.
- CHANGE/Macmillan books very good and easy to understand but the amount of information in each book is a bit daunting one patient said she felt 'overwhelmed by the information' in them.
- One carer observed that 'Health Action Plans were not read by ward staff as they are too long'. She said that the group home she works for wants to adopt a shorter document based upon a traffic light system.
- Within the appointments booking centre for Mid Yorkshire Hospitals NHS Trust there is a special role for someone to produce individually tailored patient letters if they are advised beforehand that the patient had a learning disability or any other special requirements. Adjustments for letters could be e.g. larger font, easy-read or Braille. A phone call and reminder can also be booked if a letter would not be appropriate or the letter can be sent to a nominated third party if necessary.

#### **Interviewee Suggestions:**

- Trusts should be aware of potential financial difficulties for those with learning disabilities as the frequent and lengthy appointments mean high parking, food and drink costs are incurred.

#### **Staff Suggestion:**

- The CHANGE/Macmillan cancer books ([see Resources ,Appendix V](#)) could be available on-line so that staff could print off sections as they became relevant to the patient through their treatment pathway. The pages could also be printed on individual, hole-punched sheets presented in a folder so that as much or as little information could be given to the patient or their supporter(s) at any one time.

We have spoken with CHANGE in Leeds who are aware of this feedback and have received similar feedback from other sources. They are currently looking into breaking down the information into smaller chapters to be available separately. They are also looking into the feasibility of producing these smaller booklets in a ring-bound format so that individual pages could be given/copied and updates to text easily made.

#### **Recommendation 20:**

**Some accessible information and details of where to find more should be available everywhere that offers medical treatment or advice.**

**Health staff should be aware of what is available and have copies of that information to give to patients at appointments or be able to write an information prescription for that information to be given to them at an Information Centre.**

## **Recommendation 21:**

**In light of Recommendation 18, an Information Prescription should be written for people with learning disabilities on the cancer pathway.**

### **People with Learning Disabilities Who Have a Family Member or Friend with Cancer.**

A study entitled Supporting people with intellectual disabilities who have a relative or friend with cancer (2011)<sup>39</sup> was commissioned by Macmillan Cancer Support, Principle Investigator - Irene Tuffrey-Wijne. The findings covered four main themes:

1. Information needs.  
The study found that there was 'a lack of knowledge and understanding of cancer among participants' and that 'having someone who can recognise their need for information and is willing to meet those needs is more important than having access to accessible information' (p.8).
2. The need for support.  
'The extent to which participants felt isolated and in need of emotional support was striking.... Most people with learning disabilities depend on their immediate families or care givers for support, but we found that at times of crisis caused by cancer, families may not be able to provide such support. People with learning disabilities often try to protect their own families from distress. They don't know where else they can go for support, and are unlikely to seek support from professionals' (p.8).
3. People with learning disabilities as carers.  
'Growing numbers of people with learning disabilities are becoming carers of elderly relatives within the family home, with high levels of 'mutual caring''(p.9). Without the support they need at a time of crisis, such as a diagnosis of cancer, these support networks can break down.
4. The impact of bereavement on people with learning disabilities.  
'Issues around bereavement, in particular parental bereavement, can be particularly complicated for people with learning disabilities. Complicating issues include people's understanding of death; a lack of acknowledgement for the loss, grief or mourner; complications in early parental attachment; and difficulties in keeping the memories of the deceased alive. We also found complications arising from being protected from bad news and from outward expressions of grieving.' (p.9)

Overall, people with learning disabilities who had not been told about the patient's illness felt excluded and most would have preferred to have known what was going on.

The responses from the self-advocacy groups we spoke to on the question 'Would you want to know if a relative or friend had cancer? Was that 9 out of 10 said they would want to know.

## **Patient Experience**

The Yorkshire Ambulance Service is currently conducting research into the service they provide to patients with a learning disability.

They have put together 2 surveys:

- Survey for Patients with Learning Disabilities who have used our Patient Transport Service.
- Survey for Patients with Learning Disabilities who have used our A&E/999 emergency service.

You can find the surveys at:

[www.yas.nhs.uk](http://www.yas.nhs.uk)



**The following is a comprehensive list of interviewee feedback:**

**Qs. What was good about your experience?**

- Mum: 'Can't fault the treatment she had'...'everything arranged in the first appointment, which was excellent'.
- Being given a hand massage whilst receiving cold cap treatment.
- 'Everyone was very helpful. They were all brilliant, including my surgeon – he was pretty good as well'.
- The Macmillan nurses - 'we missed the Macmillan Nurses after Chemotherapy ended'. The Halifax Macmillan Centre was 'amazing'. The open door policy and lounge where you can go for a chat at any time, even after treatment were very much appreciated.
- 'We couldn't have been treated any better than we were.'
- 'The Breast Care Nurse was very good'.
- 'The Breast Care Nurse and chemo. Nurses.'
- 'Bosom Friends'.
- Accommodation being made for a carer to stay overnight in hospital so they could be there to help and reassure the person they cared for after their operation.
- 'Pre-admission staffs were very good. They were very aware of special needs and about staff being able to accompany (the patient with learning disabilities).'
- 'The first consultant we saw was excellent...he stated that (the patient) would get the same treatment as anyone else. This was very reassuring.'

**Qs. What was not so good about your experience?**

- Feeling that after diagnosis there was 'lots to do very quickly – can't be doing with that'. 'Rushing makes me panicky.' The patient felt she needed to feel she was going at a slower pace so she could take things in and would have liked to have been given more time and understanding.
- 'Didn't explain I had to walk down to theatre' it 'was quite a way...when I felt poorly'. The patient said that she had felt out of breath and would have liked to have been offered the option of being taken to theatre in a wheelchair.
- The 'consultant seemed in a rush' – slowing down what they said would have helped not to feel so anxious.'
- 'More easy-read information should be readily available to give' so that you are 'not having to get it from websites or the Matron'.
- When staying overnight at hospital to support her daughter one mother was not offered anything to eat or drink at any time over the 48 hours she was there. She wondered if this was because her daughter was initially nil by mouth as awaiting her operation. The ward appeared to be short-staffed and there was virtually no communication unless it was sought by the parent.
- The 'Breast Nurse appeared a bit at sea with working with learning disabilities' (different nurse from that mentioned above in 'What was good..').
- A lack of communication between hospital departments. The example given was of a Breast Care Nurse organising for a carer to stay overnight in hospital when the person



they cared for had a mastectomy. When the patient and carer arrived on the ward the staff did not know anything about the arrangement and it took some time to organise the stay.

- A long wait for surgery. One interviewee arrived at hospital for a 7.15am appointment but was not spoken to until 9.30am. No-one explained the wait to her despite her carers twice asking staff present what was happening. This 2¼ hour wait caused the patient an enormous amount of anxiety and intensified her fear of what was going to happen.
- One set of interviewees did not like being given information in 'bite sizes'. Both carers and the patient with a learning disability would have liked to have known more about the bigger picture. For the carers it would have meant they could plan for the future better. For the patient it would have helped her understanding of the likely length of the treatment she would receive as she reported thinking that the experience was all over once Chemotherapy was finished and was distressed to find out that there were more appointments to come.
- One interviewee felt that there had been a lack of support from the self-advocacy group in their area, Bradford People First.
- 'Consultants/nurses didn't address (the patient) directly or ask the carers for input.'
- On one hospital visit to the ward of a patient recovering from a mastectomy, a carer found her lunch tray sitting untouched on the window sill near the patient's bed at 8pm in the evening. The carer had alerted nursing staff that the patient's drain had been leaking into the bed when she had visited in the morning. She was still sitting in the same blood stained sheets hours later at the 8pm visit. The carer concluded that no-one had attended the patient all day.
- The same carer also noted at the time that hospital staff were not washing their hands between attending patients and that gloves were not being used. When the patient was discharged to come home she was diagnosed with Norovirus and the ward she had left was closed on the next day due to an outbreak of the infection on the ward.
- A patient who had been put in a separate room off the main ward was not helped to put the television on despite being in pain and her carer noted that she felt that 'it didn't appear that people were stopping by to have a little chat with her.' When carers asked if they could spend more time sitting with the patient to keep her company outside visiting hours nurses were reportedly reluctant to let them stay: 'it was almost as though they resented a member of staff being with (her).' The carer wished a Hospital Liaison Nurse had been available: 'someone with learning disabilities training who could be called to the ward and could have helped staff on the ward with communication.'
- Ward staff post-operation 'were initially very attentive but then' tended to leave the patient alone, 'they maybe thought, if there's a problem they'll (home support staff sitting with her) come and get us.'

**Q. Do you have any ideas about how people with a learning disability can continue to share their experiences of using cancer services?**

- 3 interviewees said speaking with someone 1:1 would be the best method.
- One patient said they would like to go to a user or support group but had not been invited to any.

- 2 people thought using focus groups would be good.
- 'A forum to join on-line – a website with photos up and a 'Do you want to talk to someone?' key e.g. linking in to (local) Learning Disability Health Teams.'
- Problem – cancer not talked about in LD community.'

**Q Do you think that a group of cancer survivors with learning disabilities that includes support would be useful?**

- Yes, a separate user group for people with learning disabilities.
- 'Yes, nice for them to meet up socially e.g. a coffee morning. For all we know (the person I support) might think she's the only person this has happened to.'
- Yes, it would be useful if it was supported by Specialist Learning Disability Health Teams and day services and if they could be more aware of whom to contact for help and support with cancer.
- 'Yes, for people with mild to moderate learning disabilities.'

**Q What would be the best way for Yorkshire cancer Network or cancer charities such as Macmillan to get information to you about cancer awareness, special events, new information or screening services?**

- One patient suggested a billboard poster which 'should say what Macmillan do to support people, not just normal people but to know that people with learning disabilities get it (cancer) too.'- 'Should involve people more with disabilities', 'If they spoke to those with learning disabilities more they would get a better idea and a better understanding.'
- By placing television adverts in the middle of the soap opera screenings as many people with learning disabilities report enjoying watching them regularly. Also by soap opera characters being shown dealing with cancer. The example of Peggy's cancer journey in Eastenders was given by one set of carers who had used her as an example with the person they cared for to aid her understanding about what was happening to her, with good effect.
- By targeting day services – if a newsletter was sent out from a local centre the message would be likely to be heard. The experience of one interviewee with breast cancer has been shared with her local day service with the result that the centre has sent out a letter to all attendees and their carers to advise them on the importance of keeping breast screening service appointments. This has been well received and has prompted some much needed discussion.
- One carer said that the 'Corrie actress with the breast cancer storyline and then found she had it in real life' really helped to raise awareness. She made the suggestion that if a DVD giving information cancer was made by 'soap stars' it 'would be massive.'
- 2 x TV/radio; 2 x national or local papers; 1 x day service; 2 x GP surgery; 1 x billboard.

## Conclusions

As we have heard earlier in this report *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities* (Michael, 2008)<sup>3</sup> makes 10 principle recommendations to achieve 'an effective, fair system of general healthcare for people with learning disabilities, who also happen to have health problems (p.10):

'These recommendations concern the 'reasonable adjustments' that are needed to make health care services as accessible to people with learning disabilities as they are to other people. An annual health check; support when a visit to hospital is needed; help to communicate; better information, and tighter inspection and regulation will all work to reduce inequalities in access to and outcomes from healthcare services.

'The evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities. Although the policy and legislative frameworks are clear, there is insufficient data, poor information about people with learning disabilities and shortcomings in training. Despite guidance on the delivery of effective health care, few primary care and acute services are aware that the guidance exists, and few are aware of best practice. People with learning disabilities fare less well than other vulnerable groups in what can seem like a competition for political and local attention. Despite this, there are examples of excellent practice in a number of key areas. However good practice is patchy and, where it does occur, it is attributable to the energies of individual enthusiasts battling against the odds, rather than to systems designed with people with learning disabilities in mind. Understanding this provides important clues to the most effective way of strengthening health care for people with learning disabilities. The Inquiry believes the evidence shows that systems for assuring equity and quality of health services for people with learning disabilities need strengthening at all levels. This should start with stronger leadership and better information.'

In the Yorkshire Cancer Network area this project has found that whilst some excellent work is being done to improve equality in cancer services, there is still much to do.

## The Future

One interviewee and her carers stated their belief that one of the big problems in addressing the issue of a lack of cancer awareness and information about support networks for people with a learning disability was that cancer was not talked about within the learning disability community. They also felt that they were the ones telling their social worker about what support was available in their area. They hoped that in the future there would be more open discussion about cancer and that, with increased awareness and better communication about the support available, the experience of cancer would become less distressing for patients, families and carers.

IHAL, the Royal College of General Practitioners and the Royal College of Psychiatrists have worked together to produce A Commissioning Guide for Clinical Commissioning Groups (CCGs)<sup>40</sup> (October 2012) which aims to help CCGs to be aware of the needs of people with

learning disabilities when commissioning future health services. It is hoped that CCGs will engage with this advice and health commissioning for people with learning disabilities will thus improve in the future.

Similarly, if we are to reduce inequalities for people with learning disabilities in the cancer services they experience, all staff involved with their care, whether health staff, local authority staff, or paid/unpaid carers need to understand and take responsibility for ensuring the additional needs of this vulnerable group of patients are met. It is our hope that this report has highlighted some of the areas for concern and that, via embracing the recommendations made, inequalities in cancer services will be hugely reduced.

With the future of cancer networks unsure at this point in time, no definite undertaking can be made on behalf of the YCN to initiate or oversee any future developments in improving the equitability of cancer services in the region. For this reason one final recommendation should be made:

**Recommendation 22:**

**All those who deliver cancer services or support people with learning disabilities to access those services or healthcare in general should evaluate the services they provide to people with learning disabilities in respect of cancer awareness, prevention, diagnosis and care. Further, they should undertake to make a plan of action as to how they can implement some of the recommendations in this report within their area to improve the experience of cancer services for people with learning disabilities.**

## 6.) Appendices

### Appendix I

## Working together for better health

15th March 2012

### Notes from the day.

#### **What we did:**

Andrew Stephenson welcomed everyone to the day and introduced Sam from Inclusion North. She told us what work we would discuss –

#### **Health Inequalities for people with Learning Disabilities:**

What we know about how and why inequalities exist

#### **Initiatives & work in place to address the Inequalities:**

Sharing examples like Health Checks, Health Action plans, cancer screening etc.

#### **How Social Care Workers are supporting people's access to good health:**

Sharing what works well now & solutions for existing challenges.

**Sam from Inclusion North (focus group facilitator) outlined the major health inequalities evidence & policy responses.**

#### **What do you do to support people to have better health now?**

The big themes were:

- Use tools like pain assessments , support plans or health action plans
- Keeping good records
- Supporting people to access health services – GP, dentist etc
- Provide accessible information
- Inform about and encourage healthy lifestyle
- Promoting people's rights or advocating on their behalf
- Multi disciplinary working & good communication

You can see the full list at the end of the notes

#### **What barriers do you encounter?**

In groups we identified the barriers support staff & organisations encounter in supporting people to use health services

The big themes were:

- Not getting good information about conditions, systems or rights in the NHS

- Lack of knowledge about people with learning disabilities in health services
- Lack of reasonable adjustments
- Discrimination or negative attitudes
- Poor communication between professionals
- Lack of advocacy support or appropriate use of Mental Capacity Act

### **What is happening locally to tackle health inequalities?**

Andrew Stephenson talked about the Health Self-Assessment Framework & his role as Commissioner at North Yorkshire & York PCT coordinating the response to that.

The Self-Assessment asks areas to rate their progress on tackling health inequalities against some key targets.

You can find out more at

[http://www.improvinghealthandlives.org.uk/projects/self\\_assessment/](http://www.improvinghealthandlives.org.uk/projects/self_assessment/)

A key part of addressing inequalities has been a centrally funded scheme that supported GPs to give people with learning disabilities an annual health check.

You can read the Royal College of GPs own guidance on the health check at:

[http://www.rcgp.org.uk/clinical\\_and\\_research/circ/innovation\\_evaluation/learning\\_disabilities\\_resource.aspx#AnnualHealthChecks](http://www.rcgp.org.uk/clinical_and_research/circ/innovation_evaluation/learning_disabilities_resource.aspx#AnnualHealthChecks)

### **The Yorkshire Cancer Inequalities Project.**

Francesca Evans outlined the work she is doing as Project Manager. The project will support one of the key aims of 'Improving Outcomes: A Strategy for Cancer' (DH Jan. 2011) which is to reduce inequalities in cancer services on a broad scale and which particularly highlights the inequalities faced by people with learning disabilities:

**'Equality results from the Cancer Patient Experience Survey 2010.....** People with a disability or long term condition reported a less positive experience than other patients across a wide range of issues measured in the survey. This was particularly marked for patients with a mental health condition or a learning disability.' (p.67)

The aim is to interview those with a learning disability and either direct experience of cancer (they have a cancer diagnosis) or indirect experience (a family member or friend has a diagnosis) and also to interview their families and/or carers about their experiences of cancer care. Key professional stakeholders will also be interviewed to ascertain their perspectives on current services and patient experiences.

Francesca asked the group, who represented 18 learning disability support provider services about their experiences of supporting people.

**Q1. How many services support people who are getting health checks?**

9 services

No easy-read invitation/information letters received by any of these.

**Q2. What barriers are they encountering to accessing health checks?**

Lack of communication with GPs.

Perceived behavioural issues with the people services support and resulting potential for non-compliance with interventions or attending the surgery.

**Q3.**

**a) How many services support women in the age range for breast screening?**

8 services

**b) Of these, how many have received invites to screening for those women?**

6 services received invites.

None of these invites were in easy-read.

**c) Of those who received invites, how many services supported women to attend that screening?**

5 services supported screening.

**Q4.**

**a) How many services support women in the age range for cervical screening?**

12 services

**b) Of these, how many have received invites to screening for those women?**

8 services received invites.

None of these invites were in easy-read.

**c) Of those who received invites, how many services supported women to attend that screening?**

7 services supported screening.

**Q5.**

**a) How many services support women or men in the age range for bowel screening?**

5 services

**b) Of these, how many have received screening kits for those people?**

2 services received kits.

None of these came with easy-read information/instructions.

**c) Of those who received kits, how many services supported people to complete the screening?**

2 services supported collecting samples and submitting them.

**Q6. How many services support people to self-check for signs of cancer esp. breast and testicle checks?**

2 services

1 carer

**Q7. Do you know what Independent Mental Capacity Advocates (IMCAs) are?**

Most people present indicated that they were familiar with who IMCAs are.

**Q8. How many services have used an IMCA?**

2 services had used an IMCA – in neither case was this for a health issue.

### **Our individual actions from this workshop pledged by staff in attendance:**

Newsletter article for carers and users explaining Health Checks and rights to ask for adjustments

I will challenge GP on refusal to carry out Health Checks. If necessary contact PCT

I will join my local Patient Liaison Committee

Chase up Health Checks/Health Action Plans with GP

Ensure Everyone has a Health Check and that HCA Plans are completed

Going to find out what reasonable adjustments the local surgeries are making

Follow up on problems identified today at Scarborough

Introduce myself to Dawn Walsh, Health Facilitator for Harrogate

I will be going back to the GP and ask for the HAPs to be re-done in more detail, as at the moment they are not very good

Complete Health Action Plans for all service users

Discuss with staff team in team meetings and staff development sessions that all service users don't receive the same healthcare services with involvement from multi-disciplinary team

Contact customer's GPs who have not invited customer for their Health Check.

E-mail M Calvley at York Hospital for information

Raise awareness in the team and liaise with local services more

Try and get easy read information from GP's surgeries etc.

To share information with our team and colleagues and to make relevant information

I'm going to take all this information to our Patch meeting and cascade it to all service managers regarding Health Checks

Keep on Health Task Group agenda. Also make sure Andrew brings his paperwork to all the Health meetings

### **What next?**

We will share the notes from this meeting. Andrew will include the major issues identified in his action plans. We will share the resource list & information on the Cancer project. Thank you all for all your hard work, thoughts and ideas.

Sam Clark

March 2012

### **Full list of what people said they do to support good health:**

Staff continuity ref supporting people to health appointments

We promote that our service users are treated the same as us

Recognising bad practice within services supporting individuals to change GP etc.

As a carer I keep all doctor/hospital appointments for those I care for – continuity



We challenge our medical professionals  
Self-advocate: my mother has told me what to look for on my body to stay health  
but haven't had this from health staff  
Medication reviews  
Pain Assessment Tool  
Baseline Assessments  
An IMCA for serious medical treatment and accommodation decisions  
Encouraging choice (informed) regarding diet/exercise, dignity in nutrition/diet  
Providing information in a way/form that a person understands – from ourselves,  
health professionals etc.  
Checking understanding about health issues, information, needs, rights  
Ask people how they are, how their health is, what is their capacity and self-  
awareness like?  
We encourage our people to exercise, as they are able to  
People we support are advised around a healthy lifestyle  
Health guest speakers talk to network meeting about health, diet, exercise etc.  
Health Plans in place re: well man/woman clinics, cancer screening, dentist, GP  
etc. Discussed to address needs/issues  
We follow care/support plans and document and risk assess  
Health Action Plans and Person Centred Reviews  
Personal Support Plan  
Hospital Passports/designated key worker role  
24 hour staff cover and extra support for appointments and procedures  
our staff are fully trained e.g. epilepsy  
Training  
The need for more understanding of Health Plans from support workers/services  
We regularly carry out Health Checks as requested e.g. weight, skin integrity  
Support to register with GP, Dentist, Chiropodist  
Making sure they are registered with appropriate services  
De-stigmatise health issues  
Getting a different doctor every visit is very daunting and annoying – have to  
explain all again  
Hospitals need to offer more accessible and appropriate support  
Network with health care professionals around home visits and the Multi-  
disciplinary Team  
Communication! We listen to the people we support  
Records and discussion about medical checks – discussions around decision  
making  
Involving a wide range of people in consideration of needs  
Pen Pictures

Communications – within team and how individuals communicate comfort, pain or distress

Recording – body charts, daily notes, pain assessment tool

Involve multi-agencies e.g. psychologists, nurses, health facilitator

Prevention e.g. exercise, healthy eating

Healthy eating advice and following it!

**Barriers to supporting good health – the full list:**

- Information – relevant support, removing fear, availability/access of good information

Conflicting systems for documenting

Family understand and issues put first

Lack of staff continuity when supporting appointments

Fear of going for appointments

Lack of continuity of staff at GPs

Lack of staff in hospital for good level of care

Staff presuming issues relating to age or condition rather than a health problem.

Not investigating further

Lack of knowledge re learning disability and syndromes in GPs generally

Service users being labelled – learning disability – not their level of ability

Staff's restrictions on physical examinations

Once in hospital there can be nurse expectation that care provider stay with person 24 hours per day – unable to do this staff-wise

Assumptions made by medical staff – looking elderly/unkempt

Lack of awareness of learning disability and communication aids

Lack of communication between medical staff and both carers and themselves

Time – appointment duration (tailored to the individual)

Don't know what facilities can be accessed at home

Not being aware of possible reasonable adjustments e.g. having a Health Check at home

Environmental issues: hospital smell, busyness, waiting times, lack of accessibility e.g. signage

GPs not listening – not taking family/carer input and insights seriously

Provider not getting feedback on healthcare appointments supported by learning disability health team – dates/outcomes etc.

Lack of reasonable adjustments

GP's judgement is poor

GP and staff at the practise – negative attitude

Medical staff either fearful or lacking knowledge of how to deal with those with learning disabilities

Access – transport, aids, time, behavioural concerns

Hospital not providing facility to wash soiled clothes. If taking clothes home –risk of cross-infection  
Fear of doctors!  
GP's receptionist  
Medical staff overstretched  
Time limited appointments with professionals  
A named GP – no consistency, locums, availability of appointments, specialist knowledge or understanding, relationships  
Compassion – recognition of the individual as opposed to the medical task to be done  
Staff/provider – trouble explaining purpose of check-up  
Checks not obviously thought of by people who are well (not ill)  
Doctors/nurses performing tests without explaining them  
Behaviours that challenge  
Sharing of relevant information – recognition of the value of information from front line workers, consent and multi-agency approach  
Capacity and consent  
Not having the confidence to challenge medical staff  
Lack of advocates  
Responsibility, denial somebody else's problem, capacity  
We're depressed!  
Not a holistic view  
Lack of use of IMCAs

## Appendix II

The most recent Joint Strategic Needs Assessment (JSNA) for each area within the YCN region provides local statistics for general and, in some areas, learning disability populations.

The table below (fig.2) shows these figures with links to the full reports:

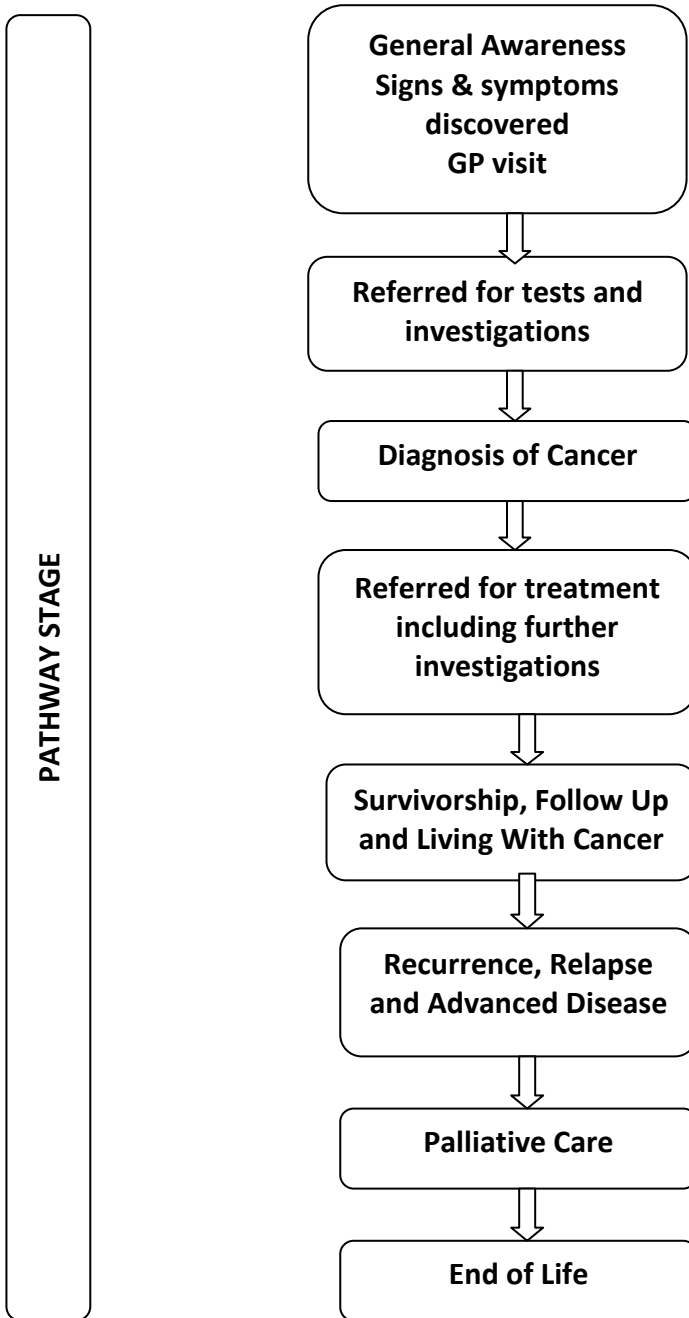
JSNA Area	Estimated General Population (year ONS statistics based upon)	Estimated Learning Disability Population Known to Services	Learning Disability Population as % of the general population.
Bradford	512,600 (2010)	8,700 Adults only??	1.7%
<a href="http://www.observatory.bradford.nhs.uk/Pages/JSNA.aspx">www.observatory.bradford.nhs.uk/Pages/JSNA.aspx</a> (all JSNAs accessed 05/09/12)			
Calderdale	201,600 (does not state year)	3,701 (2011)	1.8%
<a href="http://www.calderdalejsna.org.uk/home/">http://www.calderdalejsna.org.uk/home/</a>			
Harrogate and Craven	Harrogate 158,700 Craven 55,400 Total 214,100 (2010)	750 total (from xxx)	0.35%
<a href="http://www.northyorks.gov.uk/jsna">www.northyorks.gov.uk/jsna</a>			
Kirklees	430,200 (2010)	6,100	1.4%
<a href="http://www.kirklees.gov.uk/jsna">www.kirklees.gov.uk/jsna</a>			
Leeds	798,800 (2010)	Not Listed	
<a href="http://www.westyorkshireobservatory.org/leeds">www.westyorkshireobservatory.org/leeds</a> under Resources and Documents			
Wakefield	323,900 (2009)	6,050	1.9%
<a href="http://www.wakefieldjsna.co.uk">www.wakefieldjsna.co.uk</a>			
York	202,447 (2010)	474 (working age known to social services)	0.23%
<a href="http://www.nypct.nhs.uk/Stayinghealthy/PHInformation/docs/JSNA/York_JSNA_2012.pdf">http://www.nypct.nhs.uk/Stayinghealthy/PHInformation/docs/JSNA/York_JSNA_2012.pdf</a>			
Totals	2,683,647	25,775	0.96%

N.B. The population numbers differ slightly in some instances from those recorded in the IHAL calculations.

## Appendix III

### **General Cancer Patient Pathway**

This is a general example of a patient pathway for a cancer patient, it doesn't mirror exactly all cancer patient pathways as there are so many different ones ranging in complexity. It is included to give an idea of the method we used to draw peoples experience using different stages of the pathway to prompt their feedback.



## 7.) References

- <sup>1</sup> Department of Health (2007), *Cancer Reform Strategy*. London: Department of Health.
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- <sup>3</sup> Michael, J. (2008), *Healthcare for All. Report of the independent inquiry into access to healthcare for people with learning disabilities*. London: Department of Health.
- <sup>4</sup> Emerson, E. and Heslop, P. (2010), *A working definition of Learning Disabilities*. Durham: Improving Health and Lives: Learning Disabilities Observatory.
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