

Listening to Older People: ”” *Experiences with Health Services*

A Collaborative
Exercise conducted by
HSE Quality Improvement
Division & Age Friendly Ireland

(November/December 2014)

July 27, 2015

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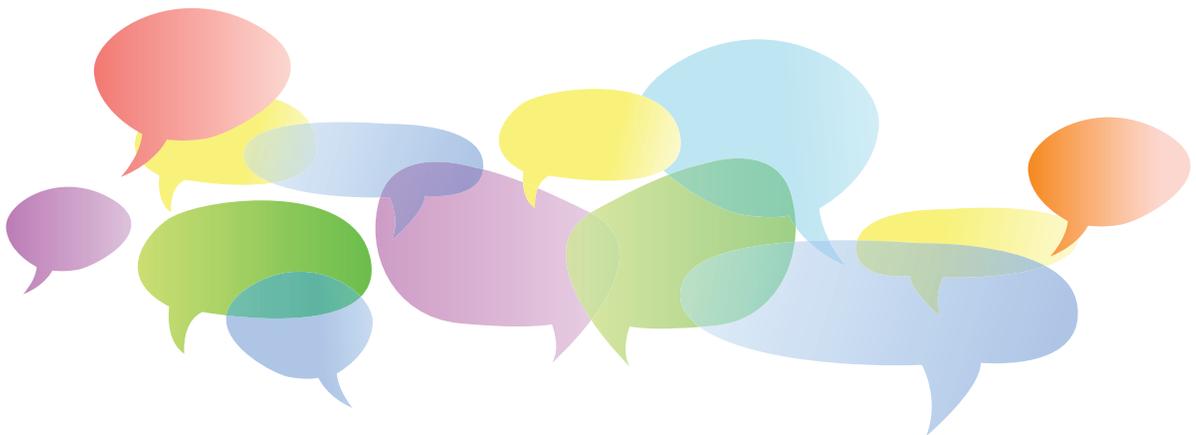
Acknowledgments

Greg Price from the HSE Quality Improvement Division and Pat Doherty from Age Friendly Ireland would like to thank all of the people who took part in the first series of Listening Meetings held in 2014 on Older People's experiences of health care services in Ireland.

We would particularly like to acknowledge and thank the 100 older people who took time to come to the events around the country and share their own experiences. This report would not have been possible without their willingness and openness to tell their stories. We acknowledge their bravery in talking about personal matters in front of others and allowing their stories to go on record.

We would also like to thank:

- » Age Friendly Ireland who facilitated the meetings through the National Age Friendly Cities and Counties Programme.
- » The Chairs of the five Age Friendly Alliances who took part and introduced the events.
- » The Chairs and coordinators of the local Older Peoples Councils in North West Dublin, Kildare, Galway, Meath and Kilkenny who organised the events locally.
- » Officers and staff of the Local Authorities and HSE who attended the events to hear first-hand what older people had to say about health care services in their area.
- » The Regional Development Consultants from Age Friendly Ireland who assisted in securing the involvement of the five Older Peoples Councils.
- » Anne Harris and Shane Shannon from HSE Quality Improvement Division for note taking at the events and for bringing together what was said at the meetings of this important dialogue.
- » Flexibus - Meath Accessible Transport for transporting people to the event in Navan.





1. Introduction

1.1 The importance of age-friendly Health Services

The Census of 2011 indicated that there are more than half-a-million (535,393) people aged 65 or older in Ireland. Along with many other countries, one of the achievements of Irish healthcare and general societal development has been the increase in life expectancy. Although many people remain relatively healthy until well into old age, the prevalence of health problems and chronic conditions does increase markedly amongst the older age groups as does the likelihood of having multiple conditions. As a result, older people tend to make more use of healthcare services than other age groups, including hospital, primary care and home-based social care.

Although we already have a substantial number of older people in Ireland, we are just at the start of a period of very rapid ageing of the population. Many other countries in Europe and elsewhere have already experienced a marked ageing of their populations, with up to 20% or more of their populations now aged 65 or older (compared to the current 11.6% in Ireland). Projections by the Central Statistics Office indicate that rapid growth in the numbers of older people is now underway in Ireland. Based on these projections, in 2016 there will be almost 90,000 more older people than in 2011. By 2031, just 16 years from now, there will be almost one million older people in Ireland, representing an 85% increase since 2011.

Year	Projected growth in population aged 65+ (thousands)
2011	535.4
2016	624.2
2021	731.9
2026	854.9
2031	991.0
2036	1,131.1
2041	1,276.3
2046	1,419.3
CSO, 2013	

“we are just at the start of a period of very rapid ageing of the population”

These developments raise many issues for the healthcare services in Ireland. It is recognised internationally that prevention and early intervention, citizen (patient) empowerment and re-organisation of delivery of care are necessary to extend the healthy life years as people grow older. In addition, there is a growing appreciation of the importance of ensuring that healthcare services are age-friendly. This means providing the right kinds of services to address the needs of an ageing population but also to provide these services in an age-friendly manner.

In Ireland, there is recognition of the need for enhancement of specialist medicine and care for older people, and this is being progressed through the HSE's National Care of the Elderly Clinical Care Programme. Likewise, there are ongoing efforts to shift resources from institutional to homecare services, even though there are currently limits on this due to resource constraints.

More generally, older people use general hospital and other health care services as well as specialist services. They use these services just like any other age group, although typically considerably more often. In these contexts they share many of the same needs as other age groups, but also may have additional issues because of their age. All parts of the healthcare system need to be age-friendly, from clinical services to the everyday customer services that provide contact to the system and services. This includes knowledge and consideration of changing needs as people get older, respect and dignity, and avoidance of discrimination, whether direct or indirect.

The World Health Organisation (WHO)¹ has identified the following as essential features of an age friendly community:

- » An adequate range of health and community support services on offer that promotes, maintains and restores health.
- » Home care services include health and personal care and housekeeping.
- » Health and social services are conveniently located and accessible by all means of transport.
- » Residential care facilities and designated older people's housing are located close to services and the rest of the community.
- » Health and community service facilities are safely constructed and fully accessible.
- » Clear and accessible information is provided about health and social services for older people.
- » Delivery of services is coordinated and administratively simple.
- » All staff are respectful, helpful and trained to serve older people.
- » Community emergency planning takes into account the vulnerabilities and capacities of older people.

Age Friendly Ireland, through Ireland's Age Friendly Cities and Counties programme, supports the roll out of the WHO's Age Friendly Cities and Communities Programme in Ireland and recognises the importance of good health care services for older people. Access to the required services and a good experience while using the services are vital for promoting the health and wellbeing of older people and enabling them to live positive and active lives in their communities.

Solutions to the challenges are being sought and improvements in attitudes to Healthy Ageing are being vigorously pursued. Citizen Empowerment is where the HSE Advocacy unit feels that it may be able to address some of the issues. The role of the Advocacy Unit has been to assist this process and to listen to our service users. Over the last number of years various projects have been developed to allow older people a voice and to empower them to make their own decisions based on the reducing resources available. A National

¹World Health Organisation (WHO), Global Ageing Age-Friendly Cities: A Guide, 2007;

World Health Organisations (WHO), Checklist of essential Features of Age-Friendly Cities, 2007

Healthcare Charter has been developed which advises patients on their rights as well as their own responsibilities in relation to healthcare, and a Patients for Patient Safety collaboration has been set up to work to improve service delivery.

The principles of Person Centred Care should be applied in age-friendly health care services:

- » Dignity, respect and compassion: Treating patients/service users and families with dignity, respect and compassion. Incorporating patient and family knowledge, values, beliefs and cultural backgrounds into the planning and delivery of care.
- » Coordinated care: Providing care, support and treatment that is personalised and ensuring that care is coordinated between services that are integrated.
- » Information sharing: Communicating and sharing complete and unbiased information with patients and families in ways that are affirming and useful and facilitates them to effectively participate in care and decision making.
- » Participation: Service users and families being treated as partners in individualised care and are encouraged and supported in participating in care and decision making at the level they choose. Enabling service users to develop the knowledge, skills and confidence to make informed decisions and to manage their healthcare.
- » Collaboration: Patients, families and health care providers collaborate in policy development, implementation and evaluation, and design and delivery of services.

1.2 Approach to the Listening Meetings

Age Friendly Ireland, in its role as an intermediary organisation, is dedicated to supporting the development of effective multi-agency Age Friendly Alliances to improve health and well-being outcomes for older people through the national Age Friendly Cities and Counties programme. In collaboration with the HSE's Advocacy Unit, Age Friendly Ireland brought together groups of older people during November and December 2014 to ask about their experiences of health services. Age Friendly City and County Programmes facilitated the process and organised the venues and the refreshments. The Advocacy Unit participated in the listening meetings which provided insights into the issues most relevant for this particular cohort of older people.

The meetings took place in Galway, Kilkenny, Meath, Kildare and Dublin, and covered both rural and urban locations. There were many similarities and common issues raised across the meetings but also some differences in the types of issues and experiences that were mentioned and discussed. Although participants reported many problematic experiences with healthcare services, the meetings were in the main very positive and constructive in tone, with very little "venting".

Participants ranged in age and situation but comprised mainly the (relatively) "well elderly" who could readily articulate their needs. However, in addition to reporting their own experiences, many were also carers who cared for spouses or siblings. Participants gave many examples of experiences of people they knew or cared for, as well as from some chance encounters of other people that they had witnessed.

More than 100 older people attended the Listening Meetings at the 5 locations across the country. Many of the individual statements by participants raised more than one issue. To

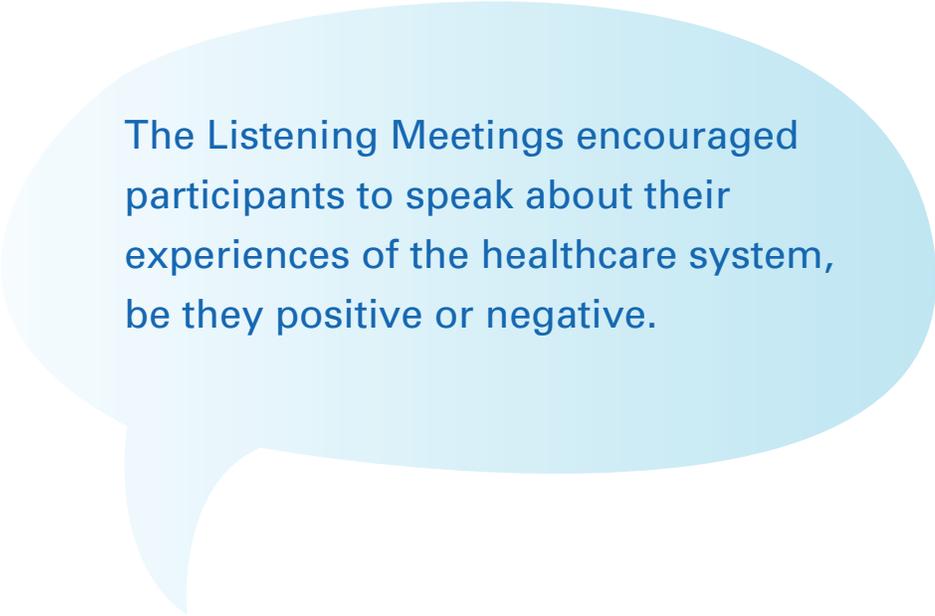
keep the report to a manageable length, a selection of the statements, in whole or in part, are presented to illustrate the main themes and issues raised.

Listening meetings are designed to elicit issues of importance to the groups who attend such meetings. They have their own dynamics that can affect the way that the discussion flows and the extent of subsequent elaboration on each theme that arises. Some issues were mentioned many times and others less often. In any case, each issue warrants consideration irrespective of the number of mentions; important issues require attention even if they are not mentioned frequently.

The Listening Meetings encouraged participants to speak about their experiences of the healthcare system, be they positive or negative. Although the majority of comments were negative in tone, there were also quite a number of positive comments about aspects of the health services. Both positive and negative comments are presented in the relevant places in the report.

The report allows the participants to speak for themselves. The issues are presented in the manner that they were expressed by those who raised them, as summarised by the note-takers. Readers may note that, occasionally, a participant statement may appear to reflect a misunderstanding of the health services and staff roles. These have not been edited, since they report on the perceptions of these issues by participants and point to inadequacies in the information provided by the health services and in communications with users.

The following Chapters present the issues and concerns that the older people spoke about. Their statements covered a broad range of issues across all healthcare settings - hospitals, primary care and social care. The statements have been grouped and ordered to a certain degree, to reflect the settings that they referred to and the types of themes and issues concerned. Where multiple statements addressed a particular theme, some examples of these have been selected for the sake of brevity. These generally come from more than one, or sometimes all of the Listening Meetings.



The Listening Meetings encouraged participants to speak about their experiences of the healthcare system, be they positive or negative.



2. Acute hospital services

Many of the participants' comments concerned aspects of hospital services. Frequently the comments addressed multiple issues and the same issues were often raised by a number of participants. There were specific comments about each of the three main settings for hospital services - Inpatient, Emergency Department (ED), and Outpatient (OPD). Some statements combined experiences and issues across all of the settings. The following is an example of this:

An elderly man spoke of the time his wife had attended a hospital in severe pain. She waited for hours to be seen by a doctor. She spent three days waiting for a transfer to a specialist hospital during which time she was on a trolley with no blankets or pillow. When she was moved to the specialist hospital he said "it was like a war zone". At one stage she was put into a small room which he called a "dungeon" with no call bell and very dark. She resorted to calling 999 from the room asking them where she was, after which she was moved straight away to a bed. Once she was in recovery, she was sent to the Day Hospital and her medications were added to. She then sustained a fall attributed to multiple medications. When she attended her GP after discharge, he changed all her medications.

2.1 Inpatient experiences

Inpatient services were addressed in many statements by participants. The issues included poor quality care, older people not treated well, lack of personal care and bed-making, and food quality.

In addition to problematic issues in these areas, there were also quite a number of positive comments about hospital inpatient experiences, with participants referring to good quality treatment, a supportive atmosphere and other positive elements of their hospital stay. Positive experiences included:

A gentleman spoke about having a fall at home. It transpired that he had a fracture and spent one month in hospital after theatre. He said that the nurses all worked very hard in that unit and that the food was very good. He was subsequently transferred to another hospital afterwards where he said he had excellent care and had a bath for the first time in months.

A lady whose husband died in 2007 spoke about how he had attended many hospitals and that they were all excellent while another spoke about the very good care her husband received in the rehabilitation unit in a hospital.

In addition to problematic issues in these areas, there were also quite a number of positive comments about hospital inpatient experiences

A gentleman spoke about the very positive experience he had in a hospital, where even though he did wait from 9am until 6pm in the Acute Medical Unit he nevertheless had a very good experience.

A lady said she had a good experience in a hospital where she received excellent care at night. The nurses introduced themselves and made her very comfortable.

However, more negative appraisals of hospital inpatient experiences predominated. In some cases the experiences were so negative that they left older people in fear of having to return to the healthcare facilities concerned. The following are some statements that illustrate this:

A gentleman said that his experiences of two hospitals were very positive but that another hospital had been dreadful and people he knew would not go there. He was particularly concerned for patients who could not speak up for themselves. He mentioned how food was left for patients who could not feed themselves and that the food was subsequently taken away untouched.

A lady spoke about the very good care her husband received in one hospital but said that the care in two other hospitals was not so good in her opinion. She is reluctant to ever return to one hospital and would prefer to stay at home instead.

A lady advised that she personally would not like to return to a hospital and that HIQA (Health Information and Quality Authority) should review that hospital unexpectedly. The lady felt that she never knew who was in charge and that older people were not treated well in that hospital.

Waiting lists and delays

A number of participants mentioned negative experiences concerning waiting lists and delays in obtaining treatment when within the system. Some examples are:

A gentleman described how he waited 2 years to have bilateral cataracts removed as his sight was deteriorating badly and eventually paid for private treatment at a cost of €7,000 which he had to borrow.

A lady said she had a setback and was advised that she would wait 2 weeks for a scope. After a long wait with no communication from the public hospital she went to a private hospital and had the procedure done under private health insurance three days after it was booked. She was finally called more than 6 months later by the original public hospital.

A specific issue for older people was the waiting list for hip replacements and associated problems with pain management while waiting for procedures.

One gentleman cited a wait of 15 months to get an appointment for a hip replacement and a further 5 months to have the surgery. He was in extreme pain until the procedure was carried out and reported being put on analgesia which did not agree with him.

A lady told of a recent experience where she was waiting for an appointment for hip replacement pre-operative check, which she was told would be in December 2013 but no word had come of it since.

Quality of nursing and personal care

A considerable number of comments concerned the quality of nursing and personal care received while in hospital.

There were some positive or neutral comments, but a large majority were negative in tone. These included issues around the type of work which nurses undertake, as well as the quality of care provided, lack of availability of nurses, call bells unanswered and staff short-ages. A number of comments pointed to the changing role of nursing. Older people complained that nurses in acute hospitals seem to spend more time writing reports than attending patients. Examples of comments included:

A contributor said that nursing is now an office job and is not hands-on like it used to be and that nurses never get to know their patients.

Another comment was that nurses should be allowed to nurse and others should be employed to do the administrative duties.

A lady, who mentioned that she herself had been a nurse, said that nurses with degrees are now academics and do not have time to spend time and communicate with patients.

A lady reported that she saw a cup of tea being left on the side of the bed of a person who had a stroke. Due to the stroke the person could not reach the tea.

A lady spoke about a close friend in her 90's who lives on her own and had poor eye sight. The lady was complaining of itchy skin and it took one year to get an appointment regarding the condition. At one point this lady needed to spend some time in hospital but the nursing staff at the hospital did not give any help to apply the cream for her skin condition; they gave her the ointment, drew the curtains and left her to apply it herself.

A man felt that the attitude of nurses in the hospital he attended was very poor and that generally the personal care of patients is left to care assistants.

A number of comments pointed to the changing role of nursing.

Other issues concerned lack of support for personal care (for example, patients being left alone to shower having had major procedures completed the day before) and bed-making.

One lady talked of being in hospital for a long period where her bed was not regularly changed but only straightened out. She had to get out and make her own bed.

Another person said that the beds are never made in the hospital she attended - she spent two weeks there and her bed was never changed.

Nutrition and assistance at meal times

There were quite a number of comments about lack of attention to nutrition, experiences of meal times for in-patients, lack of help with eating and care not being taken to ensure meals were eaten. Examples of these include:

One comment concerned the weight loss experienced by many older people in acute hospitals and that the Care Plan should document when a person does not eat.

A lady spoke about how she had to bring food to the hospital for her husband as the food was so bad.

A gentleman whose wife is currently in hospital spoke about how he was not allowed in to visit during meal times. When he came in after meal time he would find his wife's tray untouched after meals. In many cases the bed trolley is not even pushed up close to the patients where they could access the meal. He said his wife now suffers from significant weight loss and he has had to insist on being present for meals.

A discussion took place about meal times and patients not being able to feed themselves and there was no one to feed them. Participants felt there is need for someone to be there to feed them especially if they have no family.

It was also commented that family members should be allowed in at mealtimes to help feed their loved ones. Dinners are quite often cold and left at the bottom of the bed.

Food wastage was also mentioned a number of times, in the context of patients who do not eat due to not being able to access their food or not having appropriate food which they liked. The food is then taken away and disposed of.

A lady spoke about how nutrition is so important for recovery and that often food supplements are needed to aid recovery. She said that she felt that health was not viewed in a holistic way but rather by the condition one presented with.

Patient facilities and equipment

Some comments concerned the physical infrastructure and equipment, including poor bathroom design and not enough wheelchairs. The following are two examples of such statements:

One gentleman whose wife is in a Dementia ward on the ground floor of a hospital spoke about the lack of facilities for her, particularly in the bathroom where there are no handrails and no place for her clothing.

Another person commented that in one hospital she attended it did not have enough wheelchairs for all who need them.

Providing information to family and carers

Participants also raised issues about communication with the patient's family, for example:

A lady mentioned that when her husband was in hospital the Ward Sister was not able to provide her with information on his condition on a number of occasions. This was because she had been on her break when the doctor was on his rounds or had no update from the previous nurse when she started her shift.

A person spoke about a relative who had lung cancer and the fact that nobody informed her family. The lady was subsequently transferred to a Nursing Home and her x-rays were never reported on. Could all reports not go onwards electronically?

2.2 Emergency departments

Emergency Departments (ED) were also a focus of concern for participants, being directly addressed by a relatively large number of people. Issues here included long delays and quality of treatment, inadequate infrastructure, staff attitudes, and transport home from ED.

Long waiting times, trolleys

As might be expected, many older people spoke about the delays in ED and being left on a trolley for hours. Others mentioned that trolleys were not always available when needed. Examples of these statements included:

A lady described how her friend attended hospital feeling unwell and waited on a trolley for 14 hours before she saw a doctor.

A gentleman told of a time he waited for 7 hours before being seen by someone in ED in a hospital and then subsequently a further wait of 4 hours before being seen by a doctor.

A gentleman who attended with a possible heart attack waited six hours to be seen.

A person described how their relative suffering from terminal cancer arrived in ED and there was no chair or trolley for them.

A gentleman who is a cancer patient talked about his experience of waiting in ED where he was not given a trolley to lie on

Another person spoke about their experience of waiting for a day-and-a-half in ED, and being given a trolley for only 11 hours of that time.

As might be expected, many older people spoke about the delays in ED and being left on a trolley for hours.

For some people, staff attitudes and other aspects of the experience were so unsatisfactory that they left the ED without having been seen. The following is an example of this:

A gentleman said he had brought his son to ED who had a bad injury from playing football. After a long time waiting, he went to ask the nurse how long it would be before they would be seen. She told him to "sit down and learn to be patient". They subsequently left the ED and went to a private hospital where his son was diagnosed with a fractured femur. This has tainted his experience of his local hospital and he said he will be slow to go back there again; he became very upset relating the experience.

Facilities while waiting

General physical facilities were also mentioned as a problem in some cases, including lack of seating and no refreshments available. For example:

A gentleman told of a time his brother who had cancer went to the ED where there were no seats to sit down in, it was so busy. He had to wait outside standing in the car park.

A lady talked about there being no chairs for her to sit on when she attended ED in a hospital.

A lady described how she had waited hours in ED and when she asked for a cup of tea she was sent to the drinks dispenser which was so low to access and so complicated that she lost any hope of a drink.

Not knowing who's who

Another issue raised about ED concerned not knowing who the different staff were:

It was mentioned that it's hard for patients to know who staff are, due to an absence of name badges denoting their role and also that many of the staff in ED wear scrubs which makes it difficult to distinguish them.

Transport home

A number of people spoke of being discharged from ED late at night without transport arrangements, and often a taxi being the only option available. For example:

A lady spoke about attending ED and being discharged at 3am and expected to make her own way home.

A person described how their relative attended a hospital ED in severe pain at 12 midnight, waited until 2am and was then discharged home with no support, by taxi.

A lady talked about an elderly relative attending ED and having to wait for a long time there. He was told, late in the evening, that he would be kept in overnight at which stage his family went home. At 2am he was woken up and told he was being discharged. He had to phone neighbours up to come and collect him as his wife was ill at home.

A gentleman told us about his experience of waiting in a hospital ED for 14 hours and then been discharged at 4am in the morning.

2.3 Outpatient departments

A number of statements addressed Outpatient Department (OPD) arrangements and experiences. These were predominantly negative in tone.

Appointments scheduling

The need for timing of appointments to better suit older people was mentioned a number of times. Examples of these statements included:

A gentleman from outside Dublin talked about allocation of appointment times. He got an appointment for a hospital in Dublin that was early in the day. As there was no transport service that would get him to the hospital in time in the morning he had to go the night before and stay in a hotel. This all adds to the cost.

A lady said that older people are not given any priority in the timing of their appointments although it often takes them longer to prepare and to physically attend.

A lady from the Traveller community spoke in a similar vein. She commented that their home environments often did not have running water, toilets or showers and that to attend for a hospital appointment it would be preferable to have later appointments so that they might be prepared... She also suggested that literacy was a difficulty for many travellers resulting in not being able to read post and thus access the relevant information

A gentleman spoke about there being no flexibility in hospital appointments for older people who may have to travel by public transport and that there was no consideration of this fact.

Another gentleman spoke about how he had been on the waiting list for a procedure in a local facility but got a letter advising him of an appointment in a facility in another county. As he did not have transport and did not feel well enough to travel on the bus, he had to miss the appointment. He also made the more general points that older people in rural areas do not have good access to transport and these appointments are often first thing in the morning.

The need for timing of appointments to better suit older people was mentioned a number of times.

Confusion about appointments and inappropriate cancellation was also mentioned. One example was:

A lady had been waiting for a pre-op appointment which was long overdue - she was told it would be in December but had heard nothing by the following summer. As she wanted to visit family abroad, she made contact with the hospital to check on the possibility of the pending appointment. She was told that there was no chance she would be called. On her return, she was informed by the hospital that as she had missed her appointment she was now taken of the waiting list. When she checked with the hospital, they said she was never given an appointment!

Waiting times in OPD and queuing systems

It was suggested that appointments for OPD should be “staggered” so that there was less waiting around after arrival for an appointment. For example:

A gentleman mentioned that he was waiting from 9.30am to 4.30pm for a normal scheduled eye appointment. When he was seen, he had waited so long that the effect of the drops needed for the examination had worn off, and he had to have them re-administered.

A lady informed the group that she had been invited for appointment at 7.30am but the clinic did not start until 9am.

There were also some positive comments about appointment procedures that people felt took into account their needs. Existing initiatives that are in place in some locations were seen to be helpful. For example:

Text messaging services that remind about appointments are seen to be very helpful.

Ticketing systems indicating place in the OPD queue were mentioned as a positive feature.

Initiatives to augment ticket queuing system with a text messaging service to indicate the progress of the queue were also viewed very positively; this allowed the person to leave the waiting area and return on time for their appointment.

Issues
included
apparent
misdiagnosis
and delays
in seeing
medical staff
that were
felt to have
resulted
in further
health
problems

User facilities

User facilities were an issue in some cases, including seating and lack of refreshments. One example was:

A gentleman made the point that, when older people attend for appointments, there quite often won't be enough chairs; and, even though they wait hours, they have no access to tea/coffee or refreshments while, at the same time, they notice staff filling their water bottles from their coolers in the staff areas.

2.4 Hospital-wide issues

There were a number of themes raised that apply across the various hospital settings. These included issues about quality of medical care, communication difficulties with doctors and other staff who have come from other countries, and instances of neglect and possible abuse. Transport and parking were also mentioned frequently.

Quality of medical care

Participants made quite a number of comments about the quality of medical care that they had received or witnessed. Some comments were positive, but negative comments predominated. Issues included apparent misdiagnosis and delays in seeing medical staff that were felt to have resulted in further health problems, as well as issues about specific treatments and complaints about treatments in particular locations. Examples of these statements were:

A gentleman recounted how he had a fall and went to a hospital ED. After an X-ray there he was advised that it was fine, only to be brought back a week later with a fractured pelvis that had resulted from the original fall.

A lady described how her friend attended hospital feeling unwell and had waited on a trolley for 14 hours before she saw a doctor. In the meantime she had a stroke on the trolley and is now paralysed down the left side.

A lady told her story about her husband who died this year as a result of an aortic aneurysm. He had been sent home from a local acute hospital as they could find no cause for his distress. She was advised that there were beds available at the time but no staff to manage the wards. The scanning machine was also out of order. Her husband was later taken to another hospital where he subsequently died. The lady is very bitter about what happened.

A gentleman described his son's experience in a hospital, where he attended by taxi with lung symptoms and was kept in a cubicle alone for three days as they initially diagnosed TB. However, his son was subsequently diagnosed with cancer of the lung and died very shortly after the diagnosis was made.

Communication, language and cultural issues

Participants mentioned issues about doctor-patient and nurse-patient communications because of language difficulties, some of which may pose problems for effective diagnosis and treatment. Examples included:

A lady spoke about the numbers of doctors from different countries who do not understand the local accents and dialects and neither can they themselves be understood by the patients.

A gentleman recently attended the ED in a hospital and was diagnosed with a "mini stroke". The doctor was from another country and communication was very difficult. He still does not know why the mini-stroke episode happened.

A lady attended OPD in a hospital and could not understand the doctor. She made the point that many of the health care staff from abroad cannot speak English very well and that the HSE should require a high command of English before they are taken on.

A gentleman who had attended the ED at a hospital mentioned the staff from other countries and the fact that they often could not understand the patients nor could the patients understand them.

The possible impacts of cultural sensitivities were also mentioned. For example:

A lady who is an ex nurse thought that, because of cultural sensitivities, some doctors from other countries may be reluctant to ask patients to undress or to examine them without clothing. She felt this was particularly important as in her case, where she has skin cancer, the doctor did not ask her to remove her stockings to carry out a skin examination. She feels from her training that the doctor needs to be able to touch her skin to carry out a thorough examination.

Neglect, lack of respect and instances of abuse

A relatively small but nonetheless significant number of comments concerned instances of perceived neglect of patients while in the care of the health services, some of which might be considered to constitute abuse. These included perceptions of bias or disrespect towards older people (and sometimes younger people also), attitudes towards women, and general lack of care. Specific examples were:

Other issues of privacy and dignity, and sometimes personal safety, were also raised.

A lady talked about an episode of what she felt was elder abuse in a hospital. This concerned overhearing an elderly patient in a shared ward being loudly chastised by nursing staff for soiling themselves. A relative of hers had cried when she was advised that she needed to go into that hospital. The point was also made that there was no empathy, no smiles, dirty cups and untouched meals at that same hospital.

One person felt that staff have little respect for older people and never give them much time. She asked if there are sanctions imposed on staff that might be difficult or unpleasant to patients.

A lady asked why young people are not listened to in ED as she had witnessed a young patient ask about the injection she was about to receive only to be told by the nurse to “shut up”.

Other issues of privacy and dignity, and sometimes personal safety, were also raised. For example:

A lady explained that nowadays both men and women share the wards and at one point a man got into the bed with her. She could not get the attention of a member of staff and had to get out of bed to find a nurse to bring him back to his bed.

Transport

Difficulties with travel to and from facilities were mentioned quite often, especially in rural areas but also in some urban contexts:

A person spoke about the lack of rural transport and how it costs her €14 per trip to reach the hospital and that €28 out of her state pension was a huge amount.

Another participant raised the issue of the lack of transport for cancer patients to centres for treatment.

Problems were mentioned in a Dublin city area about lack of bus services and the fact that many buses have been taken off the routes due to underutilisation. This means that people from this area cannot get to their GP's or to hospital appointments.

Good examples of transport initiatives were shared at some of the listening meetings. It was felt that these should be considered by the HSE for all locations as a potential solution to transport problems, which can often lead to people not attending and a high level of no shows for appointments. For example:

Participants praised initiatives like the Flexibus service and the Volunteer Car pool which will bring cancer patients for appointments.

Older people attending from Dublin felt that problems in accessing medical facilities by bus was something which could be addressed jointly by the HSE with Dublin Bus.

Parking

A number of participants mentioned problems with parking in many hospitals, especially when the person has mobility difficulties due to their age or condition. Some people also suggested solutions. Examples of these comments included:

A gentleman spoke about the parking difficulties at a hospital. He suggested that staff parking should be at a distance and leave the closer parking spaces for older people.

Accessing the hospital from a distant parking space was mentioned as an issue for people of limited mobility. It was suggested that perhaps a mini bus could drive around the car parks picking up people as they do at the airports.

A gentleman was shocked at the costs for parking on the hospital grounds.

Finding way around the hospital

Difficulties in finding one's way around large hospitals was another issue mentioned, and that touch screens, when available, were not user friendly:

One person recently had to attend a hospital but was unable to use the touch screen system to find his way and described it as "not user friendly". He also spoke about how vast the hospital complex is and so difficult to navigate with staff unwilling to give directions and very little appropriate signage available.

A lady spoke about the local hospital being "abysmal" with nobody on reception to ask for directions.

Lack of staff to show people around and the role that volunteers might play in this was another issue:

Discussion took place about the lack of staff to direct older people to clinics, appointments etc. and the role that volunteers could play in this. A participant mentioned that volunteers are used very effectively in this way in one hospital.



3. Ambulance services

Relatively few comments were about ambulance services. There was some mention of inconsistency in response times after emergency call-outs. Other comments concerned a lack of availability of ambulances for transport home from a hospital ED or after inpatient discharge. For example:

A general discussion took place about the fact that an ambulance cannot return a patient to their home. One person said they had seen three HSE ambulances parked-up outside the hospital she attended.

However, one lady did mention being taken home by ambulance after hospital discharge in the west of the country, albeit after a long delay. She did not have access to her own transport and had to wait till 11.30 at night for an ambulance to take her home. The ambulance had to come from Dublin to take her home in Galway – in her words ‘it does not make sense’

There were also a few comments about positive and negative experiences with ambulance personnel during an emergency. These included:

One man talked about a time he slipped at home and the ambulance was called for him. While attending there was a disagreement between the two ambulance staff as to whether he should be brought to hospital or not. Eventually they brought him to hospital where he was admitted for 1 month.

Another man talked about a positive experience he had in the ambulance. The banter between the ambulance crew and himself was great and helped take his mind off the emergency he was going through.

The ambulance had to come from Dublin to take her home in Galway – in her words ‘it does not make sense’



4. Primary Care

There were a number of comments on primary care services, including GP services, medical cards, public health nursing, and other aspects.

4.1 General Practitioner services

A number of comments made reference to General Practitioner (GP) services in various ways.

Quality of care

There were some positive comments about the quality of GP care experienced, for example:

A lady who had moved to the area spoke about her “amazing GP” who is so helpful. The next speaker also spoke very highly of his GP.

On the negative side, there were also some mentions of poor quality GP care and delays in getting appointments, for example:

One gentleman said he attended his GP with haematuria (blood in urine) but his GP was not interested in following-up on this. It transpired that the man had prostate cancer and was diagnosed late.

Another speaker felt that as people grow older, the GPs approach to them is blasé – it was common to hear the statement that ‘ah it is your age’....

A lady spoke about the fact that her husband kept falling at home as a result of his blood pressure dropping. She only discovered afterwards that it was his tablets which were causing his blood pressure to drop and thus the reason for his falls.

Participants also mentioned delays in getting an appointment with their GP. One man said he waited 3 days for an appointment.

Communication of test results and reports to GPs

In the main, however, the negative comments tended to concern communications between other parts of the health services and the GP, for example:

One gentleman said that he suffered a TIA (mini stroke) and went to his GP who gave him a letter for a hospital. He was discharged subsequently but the GP never received a letter with the diagnosis or treatment to be followed. The patient did not receive a follow-up appointment for 2 years and 7 months.

Another person said that overall communication in the HSE was very poor, with reports not being sent to GP's and missing results.

One commentator suggested that it is a common experience for GP's not to receive blood and x-ray results.

4.2 Medical cards and eligibility

A number of comments were also made about access to medical cards, uncertainty about eligibility for services, and the Drugs Payment Scheme. Examples included:

A lady said that one needed a medical card to be able to access many primary care services and that many of the medical cards have been rescinded.

A participant reported that she was €1 over the guidelines and was disallowed her medical card.

A lady said that her medical card was revoked while she was going through cancer treatment and that the reason was not explained to her.

There was a general discussion about what people felt was a centralisation of the medical card provision system, with one person saying that surely local knowledge was helpful through the Public Health Nurses, Community Welfare Officers etc. who could provide this.

A lady said she would like more information about what a Medical Card entitles one to and for information provision in one comprehensive site. She also asked about the medical card in relation to dental care and was advised by others that it would only cover two fillings a year.

Another lady said that people do not know what a medical card or long term illness card entitles them to. She spoke about having diabetes and how she had to pay €25 every week for her medication. She was informed by a friend that she could avail of a discount from the HSE by filling out a form which she did and she now purchases her medication for €17.50. pharmacists (or any other health care providers) are not informing them of this entitlement.

Others spoke about how pharmacists are not including the price on their bills and felt that they are probably charging much more than the actual cost. Another person asked if the Drug Scheme was monitored.

4.3 Public Health Nurse (PHN) services

Public Health Nurse (PHN) services and issues around home healthcare were the subject of a number of comments. These included insufficient access to PHNs and not being able to get wound or stoma care:

After her husband had bowel surgery, his wife had to dress his stoma as the PHN will not do so. She looked for a Stoma Nurse to help her and could not access one.

A male speaker described how his wife had breast cancer and was on chemotherapy. He could not get a Public Health Nurse to dress her wound after surgery

A lady whose husband is currently very ill felt that there is a lack of empathy and nurses do not know their patients. They do not seem to understand that the lady cares for her husband who has to be fed, toileted and changed 24/7. She felt that staff attitude is so important and that nurses seem to lack empathy as they sit writing reports all the time.

A number of people described that they never see their PHN and the only person they ever see is the Home Care Attendant who helps them with personal hygiene.

Another participant reported that there are currently a large number of Public Health Nurses on maternity leave in their area who are not replaced while on leave.

4.4 Allied health services and health centres

There were some comments on allied health and social care services such as physiotherapy. Lack of information about available services and difficulties in making contact with health centres by phone were also mentioned. Examples of these comments included:

A person spoke highly of the local health centre and said that the physiotherapist there was excellent. However, another lady spoke about attending a hospital, where she was advised that she needed to have physiotherapy but was never sent an appointment although it was ordered by the doctor.

Another lady spoke about the lack of health services in the community and was surprised to hear that there was a Primary Care Centre in her area. She felt that communication from the HSE to raise awareness about available services was generally poor.

Participants also mentioned that it was very difficult to access clinics or health centres on the telephone as no one answers the phone.

A number of suggestions for improvement were made in these areas, for example:

Would it be possible to print a guide to local health services for older people, with phone numbers and contact details included?

There was a general discussion then about Home Care and what was available in each area, with one person suggesting that the local health office should advertise its community services in a better way.



5. Social Care

Given the profile of participants and focus of the exercise, the discussions on social care were mostly about Older Persons services and there was little reference to Disability services. Participants commented primarily on experiences of home care services, although there was some mention also of issues concerning nursing homes.

5.1 Older persons services - home care

A number of statements made direct reference to home care services, including home helps and homecare packages. Participants stressed that these services were essential to enable them to remain living at home. The importance of such services for reducing loneliness was also highlighted and a number of the older ladies stressed how help with house-keeping is so important for an elderly person. It was also mentioned by a few individuals that closing the smaller local older persons units was not a good idea.

Examples of comments on these issues included:

Participants suggested that the health service should employ more Care Assistants and Home Helps and then people could remain at home. However, the point was made that staff delivering home care need to be trained to provide this care and need to have a "caring ethos."

Access to home-care and the amount available was an issue for one participant whose husband is currently very ill.

People get frustrated when they cannot manage to do the jobs themselves so Home Help is an important aspect of care. Now that Home Help visits are being cut, home helps can no longer do vacuuming or cleaning. One lady in her 90's got very upset, saying that because of this she will not open her front door due to the state of her house, and this adds to her loneliness and isolation.

A lady spoke very highly of her Home Care Assistant but said that when this person is on holidays there is no replacement or backup. She said that it was the loneliness experienced which was more of an issue and that she missed the contact with the outside world when the Care Assistant was ill.

Many people said that services such as meals on wheels were not available in their area.

5.2 Nursing homes

Although nursing homes are an important part of the long-term care system for older people, there were relatively few statements about this sector. This may be partly because participants had little personal experience of this area and partly because their focus was primarily on hospital, primary care and community services. The comments that were made tended to be predominantly of a negative nature.

Some respondents were concerned about the Fair Deal scheme, for example:

A gentleman said that he had a sibling who is 87yrs old living in a nursing home with his wife and that he had to hand over the deeds of his house in order to receive Fair Deal. He also said that this procedure is putting people off availing of the Fair Deal scheme.

A number of other people spoke about Fair Deal as the "Unfair Deal" but admitted that it was better than nothing.

It was also commented that care in nursing homes can be good if one knows how to find and gain access to a good one.

Other issues concerned training and the quality of care provided in nursing homes. Such comments included:

A lady felt that Health Care Assistants / Attendants are poorly trained in private nursing homes and said that person-centred care should be central to all care in nursing homes.

Another lady added to this contribution by saying that public nursing homes are better managed and operated than private nursing homes. This lady also suggested that the ratio of nurses to patients should be increased to allow for better patient care.

A gentleman commented on staffing shortages, saying that in addition to shortages in community services there is not enough staff in nursing homes either.

A lady made the point that private nursing homes are profit-driven and she feels that they often do not reinvest their profits for patient/resident gain.



6. Cross-cutting and other themes

In addition to the setting-by-setting discussion of issues in Chapters 2, 3, 4 and 5, participants also raised issues of a more cross-cutting nature. These included care not being joined-up and the lack of an integrated medical records system, staff shortages, difficulties in comprehending the (ever-changing) HSE structures and services, and issues concerning private health insurance. The final section of the Chapter presents a longer case profile outlining the experiences of one woman and her husband with healthcare services.

6.1 Care not joined-up

Poor communication between different parts of the system was mentioned as a recurrent problem. For example:

A lady spoke about her experience of attending her GP with weight loss. Her GP referred her to a hospital which in turn referred her to an acute hospital where she arrived at 1pm and waited until 9pm to be seen. She had blood tests repeated in all three settings and X rays in two but never a scan and no results. She is still feeling awful and has no diagnosis.

A gentleman recently attended the ED in a hospital and was diagnosed with a TIA (mini-stroke). The place was overcrowded and he waited 3 hours thirty minutes for his tests to be carried out. The urine sample which he had submitted subsequently got lost. The doctor advised that the man should have a brain scan and an application "was lodged but lost in translation". When he attended his GP, the GP said that this was a regular occurrence.

Other participants also mentioned that, in their experience, it is common for GP's not to receive blood and x-ray results.

An ex nurse had a negative experience in a hospital where she was left for hours waiting for tests and then for the results only to find they had been lost and the tests needed to be repeated once again

A lady mentioned how she sought the records of her daughter from one hospital but it transpired that they had been transferred to another hospital and never returned.

A lady said that there appears to be no joined-up thinking in the Irish health service, with tests repeated unnecessarily time and time again. If there was an integrated computer records system that connected hospitals with the GP then there would be huge savings on unnecessary repeat testing.

6.2 Staffing shortages

Although many of the comments made by participants were critical of the quality of care received, there was recognition that this often resulted more from staff shortages than from poor quality of care from health care personnel. Examples of the comments referring to staffing issues included the following:

Participants reported staffing shortages in community care - PHNs not replaced when they are on leave, home help hours decreased and home care generally limited. Older people need some support for household duties and this no longer seems to be available.

A gentleman spoke about how he has waited a year for pain management as the relevant specialist left two years ago and has never been replaced.

Participants discussed the lack of staff in hospitals to direct older people to clinics, appointments or wherever they needed to go.

A lady suggested that the ratio of nurses to patients should be increased to allow for better patient care.

A gentleman said that everyone is affected by the cutbacks, and it's sad that his daughter qualified in a group of seventeen nurses of which only three got permanent jobs in Ireland.

A lady recounted how she was on steroids and waiting for a bone scan for a long while. She made many phone-calls to the appointments office to find out about her appointment but each time was given no information. Eventually she was informed that the machine was out of action as three of the four radiographers were on maternity leave at that time.

Another contributor said that Mental Health needs to be staffed as a 24 hour service instead of 9am to 5pm.

6.3 Knowledge of HSE structures and services

One of the issues which came up at almost every listening meeting was how the HSE had changed its structures and names of services so often. Lack of knowledge of available services was a barrier to access. Examples included:

One lady had not known there was a Primary Care Centre in her area, and only learned about this from other participants at the session.

It was suggested that the HSE create and make more widely available a register of experts in health such as Physiotherapists, OTs, GPs with special interests and Consultants and their specialities.

Participants also mentioned the re-naming of the organisation as the HSE and the subsequent cost of rebranding, even though it still seems to be essentially the same organisation. For example:

Are we not just going back to the old health boards and modus operandi?

6.4 Private health insurance costs and coverage

Earlier sections presented examples of participants using private health insurance to avoid delays in receiving treatment. Other comments concerned age-related increases in costs of private health insurance and its limited value in some circumstances. Examples of these included:

A person commented that private health insurers raise the cost for people over 65yrs and that holiday insurance also increases with age.

Quite a few people expressed their concern that they have paid into private health insurance for years and yet it is of no use for an acute episode.

6.5 Case example

This case story presents a longer elaboration of the experiences of one participant and her husband. Sadly, it provides a graphic illustration of how an elderly couple were let down by multiple layers of the system, and the many ways that healthcare services did not meet the requirements laid out within the National Standards on Health Care and the National Healthcare Charter.

Mary is a lady aged 76 whose husband, Tom, died prematurely in 2013 aged 71. They had no children. Mary tells the story of how Tom, who had been very fit, became quite ill with severe abdominal pain and vomiting when he was in his sixties. He attended a local private hospital as they both had health insurance and wanted to avoid the ED queues in the local acute hospital. On diagnosis by Ultrasound it seems that Tom was suffering from a ruptured Diverticulum (part of his bowel). He was taken to a large acute hospital where he had a scan and then an operation. After the operation he had to have a colostomy bag, but it was planned to reverse this procedure after six months when his bowel had healed.

A "Stoma Nurse" (a specialist nurse in the care of colostomies) dressed Tom's colostomy site for the first few times. However, this nurse was withdrawn due to cutbacks and the Public Health Nurse could not travel out to dress the stoma daily as she was too busy. So Mary had to learn how to carry out this procedure, which she was prepared to do until the colostomy could be reversed in due course.

After a few months, Tom was called back to the local (public) acute hospital for a Colonoscopy to see if his bowel had healed for the next phase of the procedure. This was followed, three weeks later, with an appointment in the local private hospital for a review with his Consultant. The couple asked the Consultant about the results of the colonoscopy, but he could not find them. The Consultant then carried out the reversal in the local (public) acute hospital. However, within thirty six hours of surgery, Tom became very ill. Mary was called in at 8am and met the Surgical Registrar. The Registrar was very concerned about Tom and advised that he had multiple adhesions on his bowel (where parts of the bowel stick together) and that it was torn in three places. Mary found the Registrar to be very sympathetic and caring, even suggesting that she pray for her husband.

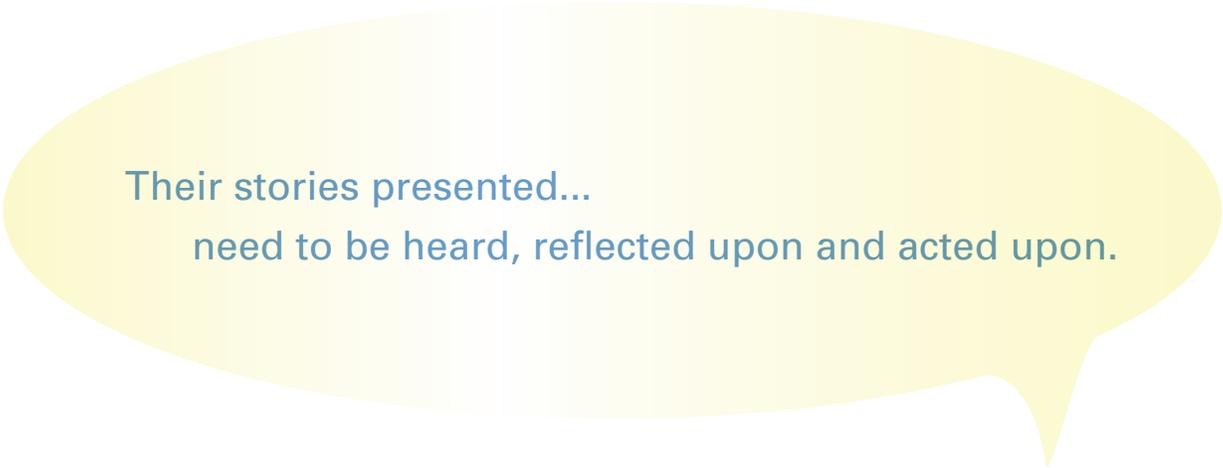
The Registrar brought Tom back to theatre (the Consultant was out of the country) and Mary believes that the Registrar saved her husband's life. He re-operated to try and save as much of the bowel as possible. After a number of weeks in hospital, Tom was discharged home but his colostomy was now very difficult to manage as Tom was "red raw" with soreness around the site. Mary continued to dress this very difficult stoma site herself as she could get no help. This went on for the next four years.

In 2010, Tom became hoarse and went to his GP and was diagnosed with Laryngitis. He returned to his GP two weeks later as he was no better. Mary said that he looked dreadful and had lost a lot of weight. The GP referred Tom to an ENT (Ear Nose and Throat) specialist where he had a scan which showed a tumour on his larynx (voice box). He was referred to a Consultant at a specialist radiation oncology hospital, where he was admitted for radiotherapy. Tom was discharged after two sessions of radium because he was too weak for more, and this was followed up with chemotherapy after a period of time. Mary continued to get no assistance with home visits.

In early 2013, Tom was reviewed again and was found to be in remission, but he had very little vocal ability and constantly felt he was choking. In August that year, Mary discovered a lump on her own breast which was diagnosed as malignant, and she was booked for a lumpectomy and removal of lymph nodes. She was due to have a number of sessions of chemotherapy prior to surgery, but was extremely concerned that there was nobody to dress Tom's colostomy site. She even considered bringing Tom to a Bed and Breakfast or to a hotel near the hospital, where she could slip out to dress the site after her surgery.

Throughout the chemotherapy, Mary was very tired and feeling low in spirits, constantly worrying about the future for Tom. Sadly, however, Tom then died suddenly at home. Later in 2013, Mary had her own surgery, with lumpectomy and removal of 16 lymph nodes. She was never visited by a nurse at home and had to attend the local Health Centre to have the drain removed. Since then she has had radiotherapy and is in recovery.

Mary is very sad to think that her husband could not have had any professional help with his colostomy bag. She herself felt quite inadequate in carrying out this procedure, which necessitated changing up to ten times a day. It leaves her very nervous about her own future and what health supports she would receive if she needed them, as she has no immediate family.



Their stories presented...
need to be heard, reflected upon and acted upon.



7. Summary

The listening meetings provided very instructive insights into the healthcare experiences of older people in Ireland. Their stories presented in Chapters 2, 3, 4, 5 and 6 need to be heard, reflected upon and acted upon. The issues relate to a range of policy and quality objectives, including those articulated in the National Standards on Health Care and the National Healthcare Charter. Some of the experiences that the participants recounted were positive but unfortunately very many were negative.

7.1 Overview of the issues raised

The Table on the following page provides an overview of the issues raised for the various healthcare settings and services.

Some of the issues have already been well-aired for years, such as long waiting times, over-crowded emergency departments and lengthy periods on trolleys whilst waiting for a hospital bed. They are not any less worrying for this, especially when vulnerable older persons are concerned. The collation of collective experiences in this report gives a stark indication of how these experiences appear to be commonplace and not isolated incidents.

Of the negative experiences, some have especially serious connotations. These include reports of unacceptable standards of care and of adverse health outcomes associated with this, as well as a small number of instances that may constitute elder abuse. More common were issues to do with overstretched services and the sub-optimal care and poor quality patient and user experiences that this leads to.

Other issues raised at the meetings have received less public and policy attention, such as concerns about how meals are provided to patients in hospitals and ensuring that elderly patients remain well-nourished, as well as limitations in the general level of attention to personal care for elderly hospital inpatients. In addition, participants reported a range of practical issues that may commonly arise for older people, such as difficulties with transport for getting to and from hospitals or other healthcare facilities, and un-accompanied discharge from ED late at night. Lack of basic facilities was also an issue, such as lack of seats in waiting areas and even lack of trolleys for patients to lie on.

Administrative issues were also commonly mentioned. Sometimes these concerned matters of clinical importance, such as test results and reports not getting passed on within the systems. Others concerned inefficiencies in appointment systems and the scheduling of appointments without giving consideration to the needs and constraints of older people. Access to basic information about health and social care services was also a problem, including lack of knowledge among older people about what services are available and how services operate.

Summary of Issues across healthcare settings & services

Health care setting		
Acute Hospitals	In-patient experiences	<ul style="list-style-type: none"> Experiences of both good quality and poor quality care Waiting lists and delays Quality of nursing and personal care Nutrition and assistance at meal times Patient facilities and equipment Providing information to family and carers
	Emergency departments	<ul style="list-style-type: none"> Lengthy waiting; long periods on trolleys; not enough trolleys Facilities while waiting Not knowing who's who Transport home
	Outpatient departments	<ul style="list-style-type: none"> Appointments scheduling Waiting times and queuing systems User facilities
	Hospital-wide issues	<ul style="list-style-type: none"> Quality of medical care Communication, language and cultural issues Neglect, lack of respect and instances of abuse Transport and Parking Finding way around hospital
Ambulance Services		<ul style="list-style-type: none"> Experiences with staff Usage of ambulances for transport home
Primary Care	GP services	<ul style="list-style-type: none"> Experiences of both good quality and poor quality care Poor communication of test results and reports to GPs
	Medical cards and eligibility	<ul style="list-style-type: none"> Access to medical cards Uncertainty about eligibility for services Operations of Drugs Payment Scheme
	Public Health Nurse services	<ul style="list-style-type: none"> Not enough Public Health Nurses Lack of home health services – e.g. wound, stoma care
	Allied health services and health centres	<ul style="list-style-type: none"> Lack of information about available services Difficulties to make contact by phone
Social Care	Older Persons services – home care	<ul style="list-style-type: none"> Insufficient availability of services Limitations on types of services provided
	Nursing homes	<ul style="list-style-type: none"> Dissatisfaction with Fair Deal Need for more staff, and appropriately trained staff
Cross-cutting and other issues		<ul style="list-style-type: none"> Care not joined-up Staffing shortages Knowledge of HSE structures and services Private health insurance costs and coverage

7.2 Next steps

This report from the listening meetings will be circulated to HSE divisions, with relevant feedback provided to each division. The divisions will be asked to put in place action plans to include measures that need to be taken to address the issues raised in the report. Discussions are ongoing on how this feedback mechanism will form part of HSE service planning.

The report will also be circulated to the relevant fora that exist within Age Friendly Ireland, in particular to Age Friendly Ireland's Board and National Implementation and Integration Group and the Age Friendly City and County Programmes (via the national convening of the Chairperson Group and the Regional fora of Programme Coordinators). Age Friendly Ireland and the national Age Friendly City and County Programmes will use the findings from these and any subsequent listening meetings in its work with health care service settings going forward, as a reference to needs identified by older people. In addition, the results will be fed back to the five Older Peoples Councils that took part in the 2014 Listening Meetings series and the lessons learnt from the process will assist in the roll out of future Listening Meetings.

It is planned that a further series of Listening Meetings will be carried out with the HSE Quality Improvement Division in the autumn of 2015. These will be facilitated by Age Friendly Ireland through its network of Older Peoples Councils attached to local Age Friendly City and County Programmes. Notes

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