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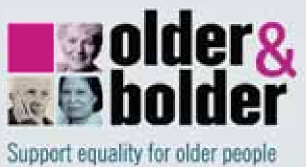
OLDER PEOPLE SPEAK UP

on health, social care and the future of healthcare financing in Ireland

MAKE HOME WORK
The right to age well at home



Older people speak up

on health, social care and the future of healthcare financing in Ireland

A synthesis of feedback from Older & Bolder's consultations with older people in April/June 2011

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Contents

Preface **5**

Introduction **6**

Background to the Consultation Process **8**

Organising the Consultation Forums 9

Scope of Consultations 9

Venues and Participation 9

Thematic Organization of the Consultations **13**

Session 1: Health and Social Care 13

Session 2: Financing Healthcare - Current Arrangements and Possible Reforms 13

Thematic Presentation of Findings **14**

Health and Social Care 14

Maintaining Health *12*

Access to Local Health Services *16*

Information *16*

Transport *16*

Care in the Community *17*

Carers *17*

Hospitals and Outpatient Appointments *18*

Nursing Homes *18*

Palliative Care *19*

Financing Health and Social Care: Current Arrangements 20

Medical Cards *20*

Medical Insurance *20*

"No Man's Land" *20*

The "Fair Deal" *21*

Financing of Health and Social Care: Future Options 22

Universal Health Insurance (UHI) *22*

Conclusions **25**

Appendix 1: Table of Consultation Events and Focus Groups **26**

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Preface

This report summarises the findings from Older and Bolder's consultation with older people during April to July 2011. In the report older people speak up about the theme of health and social care. Four fora took place in Claremorris, Navan and Dublin. Small focus group meetings also took place in two day care centres in Dublin and in a nursing home in the west of Ireland.

During the consultation, older people shared their experiences of, and hopes for, health and social care provision in Ireland. They commented on the Government's plans for reform by means of the introduction of a single tier system of health care. They highlighted the diversity of approaches older people take to maintaining and managing their own physical and mental health and wellbeing.

Some important messages emerged from the consultation. It is evident that older people value health as a resource and adopt a proactive role in managing their own health. It is also evident that, when health breaks down, the quality, fairness and transparency of our health and social care systems is crucial and that there are gaps and deficits in our current system. Access to services is affected by geography, income and the discretionary basis on which many home and community care services are available. Older people demonstrated that they want to engage in debate and discussion on the Government's plans for the introduction of a single tier system of health care but are hindered by the sketchy nature of the reform proposals available so far.

At Older & Bolder we consider it important that these messages are being disseminated to a wider audience through this report. They add a significant and informed input to the discussion on the future shape of the system of health care. The findings of the consultation have also shaped Older & Bolder's campaign, running from November 2011 – November 2012, **MAKE HOME WORK, The right to age well at home.**

I thank all those involved in the consultation process and in the preparation of this report:

- The members of the Older & Bolder alliance whose staff and networks played a vital part in the consultation : Active Retirement Ireland, Age & Opportunity, Alzheimer Society of Ireland, Carers Association, Irish Hospice Foundation, Irish Senior Citizens Parliament, Older Women's Network and Senior Help Line
- The director, Patricia Conboy, and staff, Mary Cleary, Alice-Mary Higgins and Diarmaid O'Sullivan of Older & Bolder
- Avril Dooley, Alzheimer Society of Ireland who co-facilitated meetings in day care centres
- The rapporteurs who prepared reports on individual meetings : Edel Hackett, Liza Costello and Wendy Cox
- Maura Boyle and Dr. Joe Larragy, NUIM, who prepared and edited this report
- The people who attended the consultation forums and focus group meetings and who participated with an enthusiasm and energy that delighted us.

I hope that you will enjoy and take note of the reflections of older people in this report.

Tom O'Higgins
Chairman, Older & Bolder

Introduction

The health and social care of older people has been identified as a major concern by Older & Bolder since it was established. The current system of health care, its effectiveness, funding arrangements, service quality, fairness and accessibility have also been topics of much wider debate for some time. The public-private mix of provision is a key concern in this debate, particularly in view of deepening reliance on private medical insurance, private hospital care and private long-term and social care.

There is now a serious crisis of direction about the future of Ireland's two-tier system of care. The onset of recession, deficits and debt, since 2008, has deepened this dilemma, prompting government cutbacks in public health services and attempts to curtail entitlements such as medical cards. Meanwhile the cost of private medical insurance becomes unaffordable for many due to falling incomes and rising premiums. The 2010 EU/IMF bailout has become the sheet anchor for radical "correction" of the public finances, and the certainty of deeper cuts over several years.

The recent change of government has brought with it the prospect of a radical reform of the Irish system of health and social care, championed by the incumbent Minister for Health, Dr. James Reilly. Popularly dubbed "universal health care", it is as yet only a sketchy idea with a vague implementation timeframe. The most tangible promise is that it will begin with improving access to primary care through the GP service. While services may be free at the point of delivery, the proposed reform of healthcare is not universal in the conventional sense of that term. Conventionally, universal entitlement is based on public financing of health care - either through general taxation or social insurance, or both, and providing for a similar package of services for all.

What is envisaged by the current coalition is a system of mandatory private medical insurance for all, accompanied by public subsidies for the poor. In other words, rather than widen the existing public entitlements under the current system, for example by extending the equivalent of medical card coverage to all (as in the NHS in the UK) and removing state support subsidies for private health care, the idea appears to be that everybody will be obliged to purchase insurance on the private market or from a state-owned monopoly insurer like the original VHI – with state support where a person lacks the means. The state's role will be reduced to market regulator and co-purchaser of insurance for those satisfying a means test. In the long run the likelihood would be that not only would the HSE be broken up but the traditional public service providers of hospital, community care and continuing care would be replaced by private providers.

There are many uncertainties surrounding this as yet very nebulous concept. While claiming to resolve the problem of the "two-tier" system, it could prove less equalizing than claimed, and could be prone to medical inflation, or become unsustainable if premiums continue to rise. Few concrete details have been put before the public. The envisaged scheme is to be modelled on the "Dutch" reforms which have been in operation for the past few years. There is a great deal that is unknown about how this would work out in practice in Ireland given the different history and structure of the original Dutch model. However, we do know that privately financed systems of health care are highly problematic, as for example in the US case.

It is against this backdrop that, during the months of April to June 2011, Older & Bolder embarked on a series of consultations with older people on the subject of health and social care. Older & Bolder organised a series of consultative forums for older people in the general community, in rural and urban locations, and focus groups in selected day care centres, and in nursing home setting. Older & Bolder has thus sought to begin a conversation among older people on the current state of the health and social services, to voice their views about health and social care, and express their concerns about future policy reform.

This report draws on a series of sets of written proceedings from this consultative exercise, and is designed to pull together thematically the issues emerging from the process. It seeks to convey the general and specific concerns about the current situation, articulated through the consultation process, and older people's views on the principles for the future of health and social care in Ireland.

There is now a serious crisis of direction about the future of Ireland's two-tier system of care.

PHOTO: BARRY CRONIN

PHOTO: BARRY CRONIN

Background to the Consultation Process conducted by Older & Bolder

The Consultations were designed to address a series of key themes regarding health care. These themes followed on from the "High Five" campaign organised by Older & Bolder in the run-up to the 2011 general election. The campaign was built around five campaigning points: *fairer healthcare; secure pension; local transport; my involvement; and the National Positive Ageing Strategy* (see Older & Bolder website for more details on the High Five campaign). Specifically in relation to fairer healthcare, Older & Bolder called for a universal, single tier system of health and social care with access for everyone on the basis of need; and financial contribution, through taxation or social insurance, on the basis of ability to pay. Pursuing these principles, the pre-election campaign had lobbied election candidates and parties with the following questions:

- Will you support a universal, high quality, properly planned and funded system of health and social care for everyone?
- Will you dismantle our unequal two-tier system and replace it with a universal system of health and social care?
- Will you refocus our health and social care system to develop real primary care and community care services?
- How and when will your health and social plans benefit older people?

Older & Bolder's pre-election campaign elicited some interesting responses to the questions put to parties and candidates. Fianna Fáil said that, if returned, it would maintain the existing two-tier system of health and social care. Fine Gael and Labour each had plans to introduce a "single tier" system of health care, dubbed *Universal Health Insurance* (UHI). Fine Gael's UHI model envisaged *multiple private providers* of insurance and plans for free GP access for all by 2016. Labour's UHI model envisaged a distinctly different approach based on a *single public provider* of insurance. It proposed to introduce free GP access for all immediately. Sinn Féin envisaged a single tier system financed through taxation. The Green Party would have initiated a public debate on the introduction of a single tier system of care; but said that they would immediately provide free access to GPs for everyone.

The Older & Bolder election campaign also addressed wider social care issues and commitments to specific service provision. Among the issues were:

- The financial terms on which older people will access social care services such as Home Help, Home Care Packages and supports to assist independent living at home (as distinct from health care services such as GP visits and hospital procedures).
- The focus of likely cuts in the health services. (In the election campaign, Fianna Fáil envisaged 'savings' of €680 million in healthcare as a whole by 2014, while Fine Gael promised 'savings' of €65 million from community care alone by 2014.)
- The baseline for tracking service changes. All of the political parties were proposing reform and/or extension of community care and step-down (short-term convalescent care) facilities. Older & Bolder pointed out, however, that

Ireland lacks an accurate and complete picture of the existing level of primary, community and continuing care services, including services for older people. Without such a baseline, it is not possible to establish current gaps and monitor progress over the next five years. Such a baseline could be accomplished through *HealthStat*, the HSE performance monitoring information system.

Organising the Consultation Forums

Having successfully met with politicians in the heat of electioneering, Older and Bolder's key goal in the electoral aftermath was to deepen the involvement of older people in a conversation on health policy and the ongoing process of pursuing policy development related to the interests of older people. During the months of April to June, a series of four open consultation forums were organised for older people in various parts of the country. Older people were contacted through the networks of member organisations. Contact with unaffiliated older people was sought through use of Church newsletters, local radio and newspaper listing/advertising and disseminating information through voluntary and community groups and family resource centres. In addition to the public forums, focus group meetings were also arranged for smaller groups of older people who were either attending one of two selected day centres, or who were resident in a selected nursing home. The latter were deemed important because such groups are frequently missed when it comes to voicing older people's views; yet they often have the most direct experience of health and social services.

Scope of Consultations

Whereas the pre-election campaign agenda was broader in scope, the focus of the 2011 consultations was specifically on health and social care. The themes of the consultation forums covered two broad sessional themes, first, participants' experience of the health and social services and, second, their views on the future funding of healthcare. The agenda of the first session reflected on specific issues such as ways older people help to maintain their own mental and physical health, the extent and standard of health and social care services locally available to them, and views on palliative care and nursing home care. Interest in the latter was heightened by concerns about the disruption of funding for the new Nursing Home Support Scheme[1] during 2011. The second session theme included discussions of the principles for financing healthcare and the Universal Health Insurance option being promoted by the government.

Venues and Participation

The consultation forums in hotel venues for general groups of older people began with introductory remarks from Older & Bolder staff members or board representatives. Following the open session, the forum continued through the process of a number of round tables or work groups of eight or so, with facilitators. Later, in a report back session, the facilitators drew together the comments of participants. These were recorded and incorporated into a write-up of the proceedings as a whole. This was the procedure applied in the four larger consultation forums held in hotel venues, the first of which was on 7th April in Claremorris (110 participants), followed by one in Navan on 27th April (89 participants) and two in Dublin, on 2nd June and 14th June (88 and 46 participants respectively). In Dublin the aim was to be spatially inclusive in getting information out,

1 Also called the Fair Deal Scheme.

and to elicit older people's voices in all their diversity and from a cross-section of socio-economic backgrounds. (See Appendix 1)

Smaller scale focus groups were organised. One of these was with the residents of a private nursing home in a rural town in the west of Ireland on 8th April, at which 15 out of 56 residents participated. The clients at two day centres also participated in focus group sessions. One of these day centres was located in a Community Unit in a south Dublin city suburb and took place on 27th May (12 participants). The other day centre was located in the north city centre and took place on 8th June (10 participants). In these instances, the procedure was to have smaller focus groups and to utilise methods that were tailored to the difficulties which participants might experience in engaging with the process, for example due to a disability or illness.

The high level of attendance at the consultations reflected the importance of health and social care as an issue for older people. Whether in urban or rural venues and despite the distance some participants needed to travel, the turnout at the consultations was very encouraging and provided the basis for lively input and exchange of a good range of views. In the case of Claremorris, for instance, people came from several counties, including Mayo, Galway, Roscommon and Sligo. In Navan too, people came from the wider region, including Louth and Cavan. In the case of Dublin the forum for 2nd June was oversubscribed and so a second one was organised, so that a wide range of older people was represented.

There are obvious difficulties in involving older people who are ill or frail, so it was particularly helpful to have such good representation in the two day centres and in the nursing home. The participants in the nursing home venue, incidentally, were not only very pleased to participate but asked to be kept informed of progress.

Ireland lacks an accurate and complete picture of the existing level of primary, community and continuing care services, including services for older people

PHOTO: BARRY CRONIN

Thematic Organization of the Consultations

The consultation sessions were organised along thematic lines, as set out below. However, the detailed direction of the discussion varied depending on the nature of the participating groups. In the larger consultation venues the thematic guide as a whole was followed over two sessions. In the focus groups in the day centres and nursing home, an abbreviated schedule of topics was covered.

Session 1

Health and Social Care

1. First, participants discussed ways in which older people may maintain their physical and mental health and that of people close to them. They also reviewed the availability of local programmes to encourage good physical and mental health, healthy life-styles and social interaction, particularly for men.

2. Next, the participants discussed local health and social care services for older people, particularly for those with chronic or age-related conditions like arthritis, stroke, falls, immobility and dementia, and services aiming to maximise independence and enable them to remain in their own homes.

3. Following on, the participants turned to where their nearest hospital for emergency and acute care was located, how they would get there and what their experience has been. They discussed hospital access and outpatient care, palliative care and end of life care services in their area. They also reviewed issues around nursing home care, in relation to quality and cost, and the "Fair Deal" scheme.

4. Then, medical cards, their advantages and limitations, were reviewed; also private health insurance was discussed. For example, why some older people often seek to have health insurance despite having Medical Cards. The status of older people with neither medical cards nor private health insurance was also considered.

Session 2

Financing Healthcare - Current Arrangements & Possible Reforms

1. First, participants discussed the principle of universality as applied to health care, what it is, what its potential merits might be, and related questions about a universal health care system.

2. Next, groups considered the potential "basket" of care services to be included under a universal health care system and, in light of the earlier session, the potential for financing community care services to help maintain independence in their own homes.

3. Finally, the participants discussed the principle of pooling of resources to ensure equality in the standard of care provision for all. Questions as to the contribution required of citizens to fund a universal system were also explored

Thematic Presentation of Findings: 1

Health and Social Care

Maintaining Health

In general, respondents in the wider consultations took a positive approach to health and highlighted the importance of maintaining one's own health and "taking responsibility for your own health". As some participants at the Dublin consultation agreed, "There's a lot that older people can do to maintain good health", though there can be a challenge in overcoming ageist or fatalistic attitudes that can influence one's own expectations. Maintaining health could be achieved through activities, physical exercise, normal daily activities around the house, and involvement in the community. One person in the Claremorris consultation forum noted, "It is important to use your skills in voluntary work or part time work if possible". Another key to health maintenance was keeping up contact with neighbours, family and friends. As one woman put it, "I live for my grandchildren" while another said, "the mobile phone keeps me in touch". Also, participants mentioned keeping a curiosity about life and keeping the mind active, through stimulating activities such as cards, crossword puzzles, reading, etc. Some emphasised the need for a regular routine, "It's important to have a structure to your day", and good diet, "eat well: it's fuel for life". Others stressed that it is important to try to enjoy life and have a sense of humour: "Laugh at yourself and things around you. That's what keeps you healthy."

Similarly, participants in the Navan session had a broad and positive view of health maintenance and emphasised family and grandchildren, and the importance of being "brought into the family" by relatives. They also stressed physical activities and listed a wide range including swimming, golf, dance (of various kinds), walking clubs and social activities such as clubs (drama and reading) and classes (dance and art). They mentioned a range of organisations which can provide an ongoing focus in Meath and surrounding counties (such as the Third Age Centre, the Meath Sports Partnership, the over 50s Exercise Programme in Cavan town, Active Retirement Ireland, the Navan Walking Club, and Go for Life).

The Dublin consultation forums also revealed a broad and positive approach to health care and self-maintenance through healthy eating, exercise, games, social engagement and voluntary activity in the community, with the stress on being "out and about" and "keeping your brain going". Wide ranging activities were suggested, such as snooker, bowling or choir practice, bridge and outings. Some Dublin participants were members of older people's organisations such as active retirement associations, the Older Women's Network, or were involved in neighbourhood activities. Nor were all the activities identified solely for personal benefit. Several people referred to voluntary activity and civic engagement as both a duty and a source of fulfilment and cited examples such as voluntary working in schools, English classes with non-native speakers, and nursing home visiting. Being involved in decision-making too – both in relation to their own lives and the world around them – was seen as vital to self-worth among older people.

There was awareness in several forums of a specific challenge in relaton to active participation among retired men. There was a perception that men find it more

Photo: Barry Cronin

difficult or were not as willing to mix; there were constructive suggestions and examples of innovative or good practice. At the Navan consultation forum, mention was made of The Shed, an innovative project (modelled on Australian experience) which was being piloted by the Meath Partnership in association with the Third Age Centre. Another participant commented favourably about the recent growth of the GAA Social Initiative, "There are a lot of lonely men and I think involving the GAA is a good idea". Generally, it was noted, someone should "set up more groups to interest men, who are often isolated and lonely." For example, it was noted in Dublin that the Haddington Road Centre, had organised a men's group, and there were other suggestions.

While the forum participants were keen to take a positive approach to their own health, vulnerability was also acknowledged, particularly among those living alone, the physically ill or those suffering from depression or isolation, who might also be cut off from information, or contact with peer support, while some were believed to be reluctant to go out for fear of robbery. The issue of home security was highlighted in rural areas and in the Dublin forums, though it was added that the perception of the risks in going out could be worse than the reality. Also, in Dublin, the issue of motivation was mentioned, as it affects people living alone, and there was a perception that some people were reluctant to participate, which posed a challenge. Bereavement can lead to isolation and vulnerability, and there was a need to look out for recently widowed older people. People living alone could be better served with alarm systems and adaptations to make living at home safer and more maneagable for frail older people.

An interesting point made in the Navan consultation was that older people do not want to be directed exclusively towards activities with other older people but also towards people with shared interests, regardless of age. The Dublin forums were also made aware of the diversity of older people as a whole, as for example in relation to Travellers, only 3% of whom are over the age of 65, and have very different life stories from older settled people. Traveller representatives at the Forums were keen to become involved in initiatives attended by older people. There was, in addition, a small group of people with intellectual disabilities, accompanied by a support worker, at one of the Dublin meetings.

Older people are not a homogeneous group, although they are often stereotyped as such. One common stereotype applies to the residents of nursing homes – hence the special value of the focus group in a nursing home in this consultation exercise. Interestingly, while older people in the community expressed concerns about the danger of passivity in nursing homes, the participants in the focus group at the selected nursing home had just come from a session of physical exercise, which they viewed as essential in maintaining physical fitness. They also described activities such as bingo, reading and cards, and the importance of "keeping the mind sharp". Also, they mentioned recent outings to a concert and a historic house, which they valued. They mentioned that this nursing home has a complaints service. Of course, it would be wrong to generalise about the reality of life in nursing homes based on one case. The point is that there is great value in

Photo: Stratford Photography

activity programmes and good practice development in this sector.

Similarly, the two focus groups in day centres revealed a varied picture. Participants in the focus groups in these day centres brought unique insights to the issues of maintaining health based on their experience as people who were somewhat vulnerable but also determined to live in their community. The day centres provided companionship and stimulation. These focus group participants listed a range of activities in which they engaged at home or in the day centre, including art, reading, singing, and dancing. Where people at the day centre were not able to actively participate they enjoyed watching. Some people regretted the loss of ability to continue with their hobbies, in one instance gardening and another, driving. One man previously enjoyed photography but following a stroke was unable to continue – though he still enjoyed studying photographs.

Access to Local Health Services

Many participants praised the quality of health and social services available in their areas with particular praise for primary care centres where they existed. People also spoke highly about local community centres, noting that they provided much needed supports for all ages, not just older people. However, there was wide variation in provision and quality, between geographical areas. In the Claremorris consultation, the advantages of proximity to urban centres with good primary care services were highlighted. Similarly access to specialized services such as palliative care and Alzheimer's services was influenced by geographical factors, while participants highlighted local areas that were losing GP, chiropody and community nursing services, and becoming marginalised. In Dublin, there was concern in some areas about a shortage of walk-in primary care teams, primary care services or health centres. For some, the A & E was, in effect, the primary care centre but even medical card holders must pay €20, while others are liable for a €100 charge. The D-Doc service was greatly appreciated. The restriction of some screening services, in particular Breastcheck, to women under 65, was also criticised at the Navan consultation forum. This was highlighted in the Dublin forum too. Occupational therapy services were viewed as important, for example after a stroke, but there were concerns that these were being restricted. Participants in the day centre focus groups said that chiropody was inadequately available. Medical card holders have limited entitlement to chiropody, waiting times can be a problem, and prices vary.

Information

People also highlighted the need for good local information services and various media were suggested including websites modelled on the Louth Age Friendly Website, though it was recognised that many older people do not yet use the internet. Some areas in Dublin reported being better served than others and there was an array of ways people used to get

"The mobile phone keeps me in touch"

> "We have very good experiences once we get to hospital, but getting there is the problem"

information, ranging from TDs to GPs. The provision of information in a systematic way was highlighted as an important need.

Transport

Among the barriers to involvement, transport was highlighted. For many, it was regarded as one of "the hidden costs of care". In relation to location of services, in rural areas particularly, participants were concerned about transport and access to hospital and other services. As one woman noted, in relation to rural transport, "We all have very good experiences once we get to hospital, but getting there is the problem". (Claremorris participant) In the West, the main hospitals were in Sligo, Galway, Roscommon but many services had been withdrawn. The Western region, in particular, is quite dispersed and ambulance services are limited, with a heavy reliance on family members and neighbours to get access to essential medical appointments. As one man put it, "The only way I can get to hospitals or doctors is by car but I'm not getting any younger and I'm afraid for the future." (Claremorris participant) Another commented on the traffic problems: "I might as well go to New York as Galway to hospital with the traffic jams."

In Navan, also, the transport issue was raised. In Meath, there was praise for the work of the Irish Wheelchair Association's Flexibus service. But most people were reliant on a car, either driving themselves or getting a relative to drive them to appointments. Public transport has disadvantages, particularly when there is no local connecton to the main routes. One woman's experience illustrated the problem. Following discharge from hospital she needed frequent access to the hospital but though the public bus passed a main road only two miles from her home, it was of no benefit as she had no means of travelling to meet it. While the "Flexibus" in Meath was praised as a model, it was not frequent enough and cannot cover all routes. In Dublin, there was praise for the "Vantastic" accessible taxi and minibus services where it operates in parts of Dublin. Transport was discussed in the two day centre focus groups too. In the case of the day centre in the city centre location, there was a general hospital close by, and St Mary's in the Phoenix Park provided a bus service. In the case of the suburban day centre, people reported greater difficulties and costs in accessing hospital appointments as they had to rely on expensive taxi services, or relatives.

Care in the Community

Participants stressed the importance of community care services for those living at home with limited mobility or care needs, but felt that the services were not available as readily as they ought to be, whether due to an ongoing lack of policy commitment or more recent public spending cuts. As one participant put it, "You shouldn't have to beg for home help. It's a matter of dignity." (Claremorris participant). Nevertheless, another said, "If you don't push for yourself, you can get sidelined." It was acknowledged that not everyone can do this, "It's very easy for people to get sidelined, especially if they are not able

to speak for themselves or not confident enough to speak out. They can be very marginalised." In the Navan consultation, there was similar concern about cutbacks in home help, meals on wheels, and about responsiveness in the provision of care packages and respite care. One person suggested that one would need to be "on your last legs" to get home help now. Loss of these services also adds to isolation. In Dublin, there was awareness of the pressures of time and resources on home help services, which could be difficult to access at sufficient levels. Similarly, the public health nursing service was very stretched, and some people referred to a deterioriation in recent times in the availability of community nurses.

The issue of day care as a service was also touched on by the the focus groups in the two day centres. Some wanted to have more frequent access than once per week. Others noted that there were waiting lists for a place in the day centre, and that some people were waiting a considerable time for a place. The day centre focus group participants reminded us that they typically rely heavily on home help, home care attendants and other domiciliary services, which are co-ordinated by the public health nurse. They valued these services but referred to variation in quality: some private care organisations are professional in relation to checking in and out of staff but, according to some participants, there are also care attendants or home helps who cut short their visits.

Carers

Participants regarded family or informal carers as the backbone of community care, particularly in the absence of adequate and responsive community care services. Participants were particularly vocal about cutbacks in home help and carers' supports. Some participants related their own experience as carers, sometimes looking after a parent, and the toll that round-the-clock caring can take. The first Dublin forum suggested increasing the Carer's Allowance and the second one called for the beefing up of supports for carers, as critical policy challenges. Respite care for carers was highlighted at one of the Dublin consultations: as one participant, herself a carer, noted, "It frees me up".

Some participants related their own experience as carers and the toll that round-the-clock caring can take

Day care clients also rely on relatives and carers, as the two day-centre focus groups highlighted. Respite was a key service both for family and for the older person. One of the day centres adjoined a unit where residential respite care was provided. This worked well as the clients

Photo: Barry Cronin

knew the staff and could maintain contact with the day service while staying over for respite. In the other unit, the respite care had been available but was not any longer provided on site, apparently due to funding cuts and other calls on the beds. Respite was provided elsewhere and some of the clients would have preferred the familiarity of the original arrangements.

Hospitals and Outpatient Appointments

There are three hospitals serving the north-east region – Our Lady of Lourdes in Drogheda, Cavan General Hospital and Our Lady's Hospital in Navan. While participants in the Navan consultation were in favour of centres of excellence, there was concern about the downgrading of services in some hospitals. Broadly, there was a positive experience of quality of care within hospitals. Some instances of hygiene problems were mentioned. The ongoing problem of waiting on trollies was also raised, and it was felt that you had to "fight your corner". Better after-care and step-down facilities are needed to free-up acute hospital care, it was felt by some contibutors.

An issue that frequently came up was the way outpatient appointments are organised. Often, several outpatients are asked to come to attend at the one time and then wait to be called, rather than at a scheduled time which might reduce the time spent sitting and waiting. As one Claremorris participant put it, "You have to get up at the crack of dawn to get there for 9 a.m. When you get there you find you're sitting with lots of others with the same time. Then you don't get seen until 12." A similar comment was made by a participant in Navan, "Why are all hospital appointments made for 8 a.m.?"

In some cases, when people needed to travel a long distance, they had to leave very early in the morning or travel the night before, which could be very costly. This issue is really quite important in that

Photo: Barry Cronin

older people awaiting appointments may have several conditions, for example diabetes, which necessitates regular eating routines. Some older people have problems with incontinence, and find the waiting arrangements very stressful. Others, again, referred to having waited so long and been so stressed that by the time they were seen they had forgotten some of the things the wanted to mention to the doctor. The nursing home focus group also mentioned lengthy periods of waiting, due to bunching of appointments at the one time at outpatient services, and waiting times in hospitals was also a source of complaint among day centre focus group participants. In Dublin, many people at the consultation referred positively to the treatment they received in the major hospitals. However, people also referred to the two-tier experience in relation to waiting for treatment in public versus private hospitals.

Another big issue for many is parking. Access to parking space can be a problem, while the high cost of parking at hospitals, which is now strictly enforced, is another issue. Waiting times in hospital A & E departments makes the parking issue even more problematic.

Nursing Homes

People in the community level consultations were keen to avoid going into nursing homes for as long as possible. There was a thread running through participants' observations on nursing homes – fear and a desire "not to end up there". They expressed

concerns about a lack of stimulation and a loss of engagement in institutional environments. One person heard of a nursing home where residents were put to bed as early as 5pm in the evening due to the inadequacy of night staff. Another noted that she never wanted to go into a nursing home: “I don’t like them. I’ve told my husband never to put me into one. Everyone’s just sitting there or walking around, lonely and down.”

It was acknowledged that nursing home care was a solution for some people, especially those who would prefer to be there rather than become a 24/7 burden on the family. For others, the prospect of going into a nursing home provoked a strong “fear of the unknown”. Concerns about the variable quality of nursing homes were expressed, for example in relation to regular review of medication, the risk of over-medication and “sedation”, and the mixing of residents who are sound of mind with residents in advanced stages of dementia. There was a role for relatives in being vigilant and engaging with the nursing home. In Navan, people had the impression of variable quality of care in nursing homes, with hygiene issues in one case, while high cost was another issue. People suggested the provision of more alternatives, including local retirement villages with facilities for congregating. There were also issues relating to the delays in transferring from hospital to nursing homes.

On a positive note, as referred to already, stimulating programmes and exercise were integral to life in the selected nursing home from which residents participated in the Older and Bolder focus group. Also, the residents’ focus group reported that they had weekly visits from their GP, the matron arranged the collection and distribution of medicines, and a chiropodist visited monthly, and this service was free. It was more difficult to access services off the premises. Visits to opticians, and other social or medical services, entailed getting and paying for a wheelchair accessible taxi. It was similar in relation to the nearest general hospital – located 20 miles away – and outpatient visits. Apparently such transport used to be subsidised but that was no longer the case.

“Laugh at yourself and things around you. That’s what keeps you healthy”

Palliative Care

The home visiting palliative care nurses were praised highly in the Navan consultation. However, there were concerns about the availability of palliative care in cases other than cancer, and a suggestion that “it is good if you can get it” but availability varied and “depended on local funding”. Also, there was no hospice in some areas. Apart from the funding issue, the provision of more local information was also mentioned. There was praise for the hospice care in Harold’s Cross and St Francis’ Hospice, Raheny. Restricted access to palliative care was mentioned as a concern in Dublin too. In the second Dublin consultation, one participant felt that palliative care was too limited – both to specific illnesses and to the very last days of life, and should be more widely available.

Financing Health and Social Care: Current Arrangements

Medical Cards

The medical card was acknowledged by many to provide peace of mind and reduce financial worry over medical care costs for a majority older people. The key benefits of medical cards were typically identified as free GP care, free hospital care and other services, including optical and hearing care, within limits. Medication was free, until a new 50 cent charge per item was introduced in the 2010 budget. Some people had experience of gaps or weaknesses, such as delays in hospital admissions, charges for blood tests by GPs, and a perceived lower quality of service. Fears of new restrictions on medical cards, particularly since the revocation of automatic entitlement for the over-70s, have become a source of anxiety. There was some confusion as to the precise entitlements of medical card holders, for example in relation to chiropody and physiotherapy.

In Claremorris, some felt that there was a stigma attached to the medical card: "Medical card holders can be treated as second class citizens." One woman at the Claremorris forum suggested, "Doctors don't have the same interest in patients on medical cards." This sentiment was echoed in Dublin, where some participants felt that there was a stigma associated with being on a medical card. In Navan, it was suggested that with the medical card, patients were mainly seen by junior doctors, and there is less access to consultants. A number of participants believed that there was a two-tiered system in relation to how quickly the public patient will be referred for X-rays and other tests, in contrast to the prompt treatment of patients with private medical insurance. A small number of people felt that there could be abuse of the medical card system. However, many agreed that: "you're more likely to go to the doctor before it becomes a big issue if you have a medical card."

Medical Insurance

Despite the fact that a majority of older people have medical cards, some – despite the obvious expense – seek to top it up with private medical insurance. The reasons indicated include "peace of mind", and getting speedier attention, particularly from hospital consultants. As one woman in Claremorris put it, "It gets you in much faster". One person in Navan bluntly noted, "You could die on a list". Several Dublin participants expressed a "lack of faith" in the public system, and in the medical card, in relation to timely access to hospital care.

On the other hand, there was clear concern about the rising cost of medical insurance, or, as one participant in Claremorris put it, bluntly, "Private

"You're more likely to go to the doctor before it becomes a big issue if you have a medical card"

healthcare is a rip-off." A Dublin round table participant described the cost as "prohibitive". Many participants found the whole pricing and benefits of insurance confusing and wanted clear information to help make informed choices. Many older people had paid into private medical insurance all their adult lives – and they had got used to it –and so it galled them to think that now, when they needed it most, they could not afford it and might have to give it up. In Navan, one person noted a lack of transparency in relation to payments made for beds and treatments, and had direct experience of inconsistencies. A Traveller participant said that older Travellers could not possibly afford health insurance.

"They have to choose between doctor, bills, food, living or dying"

"No Man's Land"

In more than one of the consultative forums, participants referred to the "no man's land" or "limbo" of having neither medical cards nor private medical insurance. While a few believed that older people who were ineligible for medical cards were probably able to afford private medical insurance, most were less convinced. This disentitled status was viewed as a great source of distress, particularly in relation to GP services and medicines, with potentially bad consequences for health practices designed to save on costs, including self-medication and ignoring symptoms, and failure to visit a GP. A Dublin forum view was that this group "can't afford to get sick!" While they are entitled to free public hospital care, and wait on a list, they will have to pay out-of-pocket for primary care, medicine, the €100 A & E charge, private consultants, etc. As one contributor put it, "(they) have to choose between doctor, bills, food, living or dying".

The Nursing Home Support Scheme

The current operation of the Nursing Home Support Scheme (also called the "Fair Deal" scheme) for supporting long-term care in nursing homes worried some participants. In the Dublin consultations, a few took the view that the Fair Deal was a good model, "you pay only for what you need, not for what you might never need". Many others expressed a need for greater clarity on how the scheme works in detail. One contributor to the discussion in Navan mentioned the fear of losing a farm, in a case where, after the death of the resident, the farm might be sold over the heads of her sons whose livelihood was farming the land. Members of the Active Retirement movement and Senior Citizens Parliament said they had not endorsed the "Fair Deal" scheme. In the period running up to the Dublin forum, there was a lot of coverage about temporary suspension of the scheme and under-spending on the Nursing Home Support Scheme. (It later emerged that €100m from earmarked funds had been shifted to other purposes. Following a public furore, the funding was reinstated). This media focus gave rise to serious concerns among the participants, who were bewildered at why funding should be withdrawn from such a vulnerable group, and to calls for much greater accountability. Some felt that the "Fair Deal" should be the focus of campaigning and there were concerns about cuts or changes for the worse in the future.

Financing of Health and Social Care: Future Options

The future financing of health and social care was a major concern at the forums. Under the current, "two-tier" system, those with private health insurance typically experience better access, shorter waiting times, and superior quality of health and social care than those who rely on the public system. Older & Bolder has been calling for universal health and social care for some time. Under a universal health and social care system, everyone would have the same access to health and social care, and care would be provided on grounds of need for care or urgency of illness.

There was broad support for a genuinely universal system of health care that was free at the point of delivery and that could overcome the "two-tier" system we have at present. As one contributor humorously put it, "It would be lovely: if you're ill you wouldn't have to stop at the bank to see if you have enough money to pay for your care." However, there are various ways to deliver a unified system, as illustrated by the range of systems that operate in other countries. As yet there has been no debate on the range of options or the constraints arising from historic or other factors in implementing potentially major reforms in the Irish health system.

Universal Health Insurance (UHI)

It was explained at the forums that both Fine Gael and Labour's pre-election manifestos contained plans for introducing different models of *universal health insurance* (UHI) and that in its Programme for Government, the new coalition intends to follow through on a compromise between both models. While no details have yet been provided by the Government, its Programme for Government promises a system where 'access will be according to need and payment will be according to ability to pay.'

The concept of Universal Health Insurance was thus an important topic at the consultations. Nevertheless, despite an outline of the role of insurance in the proposals of Government, many people were confused by the term "universal" and believed that the government were referring to social insurance along the lines of PRSI. Since the Government has not set out how the system might operate, it was difficult for participants to provide substantive responses to the proposals . Therefore, there were mixed reactions and calls for more information and clarity.

One person wondered whether there might be a bias against older people in a system based on universal private insurance, cautioning, "Any new system shouldn't make the practice of ageism greater than it is now." Some concerns were expressed over the possible loss of the entitlements provided through the medical card: "For people with a medical card, we've no fault with it. With this new system we may be asked to pay something (more). The problem is where does it end?"

In Dublin, while a move towards a single system had promise, participants felt that "equality must mean equality" and the "same high standards for all". "Before welcoming anything", one group noted, 'it would have to be a good system, meticulously planned and with a guaranteed set of conditions'.The view was that if the system was "up to scratch" the population would pay, according to their means.

There was scepticism about universal health insurance at some forums: "We do need a fairer health system but I don't see (UHI) working." In a straw poll on UHI at a round table in the Claremorris consultation forum, five were against, two in favour and two undecided. Some

genuinely wondered whether the present public system could be made more effective than opting for a radical shift to UHI. One person suggested that it might be one "broken system" replacing another.

The challenge of bringing about such a major shift in policy, and the transitional arrangements during the changeover would be substantial. One working group was so concerned at the magnitude of the changes that they thought a referendum to approve the change would be necessary. As someone pointed out in Navan, "The devil was in the detail", and there were a lot of detailed ramifications entailed in such major reforms. Many questions on how the system would operate were raised at the Dublin sessions too. These related to how much we would pay, what would be in the basket of entitlements, whether pensioners would have to pay, whether everybody would have exactly the same entitlements, the inclusion of social services and community care, and other important facets.

At the simplest level, participants were concerned about where the funding would come from, particularly in the current climate, to sustain a universal system: In Claremorris, it was asked, "Who is going to pay for it? Is the country able to pay for it? There is a need for more doctors and nurses but who is going to pay them?" and "This is going to take a lot of money and the country hasn't got money!" While this might sound pessimistic, it highlights the need to spell out more clearly the alternative funding options and the feasibility of new approaches. This in turn calls for political leadership, public information and awareness-raising campaigns and activities by decision-makers. The consultation experience demonstrates the appetite and capacity of 'ordinary' people to engage in debate and discussion on quite complex policy issues – if the information is provided.

Another set of issues related to the way that premiums would be decided, and the impact of a means-test to decide who contributes, and how much. This in turn pointed to the issue of whether the existing infrastructure for service delivery would be adequate to meet the demands of all in a single tier system, without rationing and waiting lists. While people were broadly in favour of ending the two-tier system, they were conscious of the challenge. Some feared that people might over-utilise services that are free to the user: "You should pay something for the health system. If you are paying even a little it might stop them going in so often." What most people wanted was a system that was transparent, effective and fair for all.

The proposed UHI concept needed to meet certain criteria: would it produce a fairer, more equitable system than the current two-tier model? Would it assure everybody of health and social care services regardless of their income and would it lead to reduced waiting times for scans and treatments currently experienced in the public system? Could it possibly be contemplated in the current economic climate?

What people wanted was a system that was transparent, effective and fair for all

Conclusions

Any exercise of the scale and nature of the consultative process undertaken by Older & Bolder is ambitious and poses great difficulties in pulling through the principal threads.

A key theme to emerge from the consultations is how older people value good health and wellbeing, and recognise the importance of taking care of themselves and having a positive attitude to health, as a resource. However, when health breaks down,the focus must shift to the curative and care provision levels, the quality of the service and response time, the transparency and fairness of the system.

Inevitably there will be confusion among the general population over the detailed and changing "terms and conditions" underpinning access to healthcare system and proposed policy changes.There will always be some dispute as to the precise details in relation to more technical issues. Yet there is great value and validity in the knowledge generated by the overall process.

The value of the consultation process is that it has enabled older people to articulate issues based on their experience of the health service in practice, and provide the kind of knowledge that otherwise may be passed over – the irritating things that go wrong, the hidden costs of health care, the gaps in service, the failures in quality, the hidden strains in families.

The way things work on the ground is often at variance with what policy makers might aspire to when developing policies and planning services. Variations in experience due to geographical, economic, social, institutional and attitudinal factors, and a range of other circumstances, are important and need to be brought into the equation.

However, the main differences in the experience of health and social care services in Ireland are not due to unanticipated consequences but have been embedded in the system as intended from its beginnings.The single major factor identified is whether a person has full access to the range of required services at the point of delivery. A primary division here is whether a person has private health insurance or not. Having a medical card is the alternative mechanism – and the principal one for many older people.

Neither is perfect, however, and some - those older people who can manage to pull together the resources - have found that the key to getting good care is to have both the medical card and private health insurance. Older people in this position are in a minority and, for a variety of reasons, this combination is getting harder to sustain and, in fact, increasing numbers may be finding themselves with neither a medical card nor private health insurance.

The consultation exercise is particularly important in view of the prospect of radical changes in the financing and delivery of health care in the future, and the high hopes which the government has for the outcome of planned reforms. It is really vital that the debate on these changes begins now and that older people are at the centre of the debate. A key issue here is the very sketchy nature of the government's proposals so far and the total lack of any detailed descriptive account of the proposals or evaluative analysis of their potential effects.
These absences were highlighted in the consultation process. If the consultation has brought even a few of these issues out into the open for further public discussion in the coming months and years, it will have done its work.

Appendix 1:

Table of Consultation Events and Focus Groups

Date	Consultation Event	Venue	Attendance	Rapporteurs
7 April 2011	One For All – Health and Social Care in Ireland (Consultation Forum with Older People)	McWilliam Park Hotel, Claremorris	110 12 work groups	Edel Hackett
8 April 2011	Older & Bolder: Health and Social Care Forum (Focus groups with Residents)	Selected Nursing Home, rural town in west	15 out of 56 residents	Diarmaid O'Sullivan Alice-Mary Higgins
27 April 2011	One For All – Health and Social Care in Ireland (Consultation Forum with Older People)	Ardboyne Hotel. Navan	89 11 work groups	Liza Costello
27 May 2011	Focus Group among Day Care Centre Participants	Day Care Centre in Dublin city suburb	12 clients	Avril Dooley Alice-Mary Higgins
2 June 2011	One for All – Health and Social Care in Ireland, (Consultation with Older People)	Aisling Hotel, Dublin	88 12 work groups	Liza Costello
8 June 2011	Focus Group with Day Centre Participants	Day Centre in north Dublin city centre	10 clients (9 female)	Avril Dooley Alice-Mary Higgins
14 June 2011	One For All – Consultation Forum with Older People (Round Tables)	Aisling Hotel, Dublin	46 6 groups	Wendy Cox

Older & Bolder is an alliance of eight organisations in the age sector in Ireland –

Active Retirement Ireland,
Age & Opportunity,
The Alzheimer Society of Ireland,
Carers' Association,
The Irish Hospice Foundation,
Irish Senior Citizens Parliament,
Older Women's Network &
The Senior Help Line.

Independent Chairman: Mr Tom O'Higgins.

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