

Do-It-Yourself Citizens Jury

Newcastle upon Tyne

Jury Verdict

Funded by the Joseph Rowntree Charitable Trust

**Coordinated by the DIY Jury Steering Group and the
Policy Ethics and Life Sciences Research Institute,
University of Newcastle.**

January 2003

Introduction by the Citizens Jury Steering Group

The Newcastle DIY Citizens Jury began when a group of older people from around Tyneside came together in March of last year to start planning the first ever Do It Yourself Jury. We were among the sixty people who discussed ways of improving policies that affect older people. Most of us hadn't met each other before, but what we had in common was that we wanted to change things for the better for older people.

Over the following weeks we met seven or eight times to decide what the subject of the jury should be. Usually in a citizens jury, the subject is decided by a Local Authority or a government body. But in this Do It Yourself Jury, it was us who were in charge.

We chose a topic and experts with a range of perspectives and knowledge. The subject of our jury was falls among older people, in particular the development of new health technologies which might reduce falls.

Falls are not an issue commonly thought about by most people. Despite being older people ourselves, none of us on the steering group had been involved in discussions on falls before. Having been present at the hearings of the jury, we have heard how falls can be the most important trigger that can turn an able-bodied older person into a disabled or infirm one.

We have three concluding points.

1) Consultations are often full of good intentions, but are based on the preconceived ideas and agendas of the commissioning body.

Here, ordinary people have been in charge – there was no commissioning body. The steering group is in control of the process. The facilitators are there to do what we want.

2) In a normal consultation there is lots of jargon. We make sure we are all talking the same language. Jargon is used by people who want to get their own way. Jargon is a way of talking down to us.

3) This is an experiment. We are making mistakes, but learning from them.

We are making a handbook and video for others who want to run their own DIY Jury. Details of how to get your copy are at the end of this report.

We commend the following verdict to you and hope that you will join with us in using it to improve older people's quality of life.

Jurors' report

We, the Newcastle Citizens Jury, were asked to consider the following question:

How can new health technologies be designed and regulated such that the lives of older people are improved, not merely lengthened, particularly in relation to falls?

The following recommendations were agreed unanimously unless stated otherwise.

We recommend the development of a **multi-disciplinary falls pathway** to coordinate and improve the care given to older people prone to falls. This pathway should be controlled, coordinated and monitored by a falls pathway unit based at the relevant local hospital.

This pathway should provide a seamless service for prevention, treatment and after-care of:

- a) *Those thought to be prone to falls.* Includes those with early Alzheimer's, dementia, diabetes, osteoporosis, those receiving chemotherapy, people starting new treatment to lower blood pressure, etc. These people should be subject to a preventive regime.
- b) *Those who have already experienced their first fall.* There should be active intervention to reduce the risk of further falls at home and in their daily routine.
- c) *Those who have experienced repeated falls.* More radical intervention might be considered in association with the person who has fallen and others concerned.

Specialist services coordinated in this pathway should include:

- Physicians/orthopaedic surgeons
- Physiotherapists
- GPs & Community nurses
- Home helps & Social services
- Community groups doing prevention work

The pathway should make use of:

- Appropriate information technologies and databases used by the falls pathway [above].
- A varied approach to communication perhaps including TV soaps, adverts, drama, the internet, multi-language to include all communities of older people and multi-media.

Elements of the falls pathway

1. Information pack for everyone

At pensionable age, all older people should receive an information pack from the government which would outline:

- entitlements e.g. extra heating costs, TV licence concessions, benefits available and where to apply for them
- promotion of health – exercise, diet
- information on classes, groups, meetings etc in local area
- information on NHS provision – well-being check-up / how to access services
- information on agencies (e.g. Citizens Advice Bureau) where they can access information and get assistance with form filling etc
- details of charities that exist specifically to assist older people
- promotion of the benefits of living in a safe and warm environment (information on grants that may be available to help – insulation, social services assistance with rails etc)

The pack should include details (in different languages/Braille) on how to receive the information in different languages/Braille.

It should be written in plain language with no jargon.

2. Older people's community groups

- We support community groups such as Old Spice, which use drama to increase older people's interest in prevention.
- Old people's community groups need more integration into the mainstream NHS or care services - both involvement and funding. Such groups are effective at getting more information out into the community to promote lifestyles that promote older people's confidence while minimising their risk of falling.
- The misery avoided and money saved by such preventative measures are very difficult to quantify, but we believe they are effective, so this lack of statistics should not stop them being put in place.

3. In the home

- Home help/community nurse to review home circumstances on a regular basis and check for physical dangers in home environment and in daily routine (shopping etc).
- Encourage adaptations to existing homes so people don't have to leave their homes (e.g. staircases wide enough for stair-lifts,

doors wide enough for wheelchairs). In more serious cases, older people should be encouraged, but not forced, to move to more suitable housing (sheltered accommodation/care homes). This should be of a high standard of comfort, with plenty of natural light.

- The principle should be the promotion of independent living for as long as possible.
- When new housing schemes are built, current regulations require that a proportion of them should be affordable to those on lower incomes. We believe there should also be a requirement that a proportion should also be built with older people's needs taken into account.

4. Home emergencies

- There should be an NHS provision of a central service to respond to emergency calls on easily used/understood single purpose mobile alarm/phone,
- Around 20% of older people live alone. All elderly people living alone should be provided with an emergency alarm if GPs feel the person is at risk of falling. This should be provided free by the NHS.

5. GPs/Local clinics

- We recommend that GPs should be encouraged to hold clinics that particularly focus on older people at risk from falls. GPs and other concerned health professionals could then refer older people to the falls pathway unit from their own falls clinic.
- Only a small proportion of doctors training focuses on issues that affect older people. Doctors should have more training regarding the needs of older people and particularly the dangers of multi-prescribing.
- There should be more training for GPs on alternatives to drugs as well as drug side effects (to stop them over prescribing).
- GPs to be actively encouraged to review elderly patients on multi-medication at least on a 3-4 monthly basis, and not rely on endless repeat prescriptions.

6. Falls centres

- Specialist one stop falls assessment centres (like the one we heard about from Rose Anne Kenny), should be encouraged. The

Newcastle system should be compared with other such systems in the country in order to look for ways to improve the services provided.

7. Rehabilitation

- Rehabilitation should be re-introduced as a service provided to older people by all hospitals.

8. Nursing Homes

- Nursing homes should have better trained and better paid staff. Residential home staff should be trained on medication and its potential side-effects. They should be able to check overall health, not just hand out medication.
- Training should emphasise the benefits of reducing prescription dependence – producing a reduction in falls. (We are particularly concerned about sedatives, which we believe to a causal factor in many falls. We believe that measures to reduce sedative prescription in the US have led to a drop of a third in falls in nursing homes.)
- Nursing homes should provide more occupational therapy and give more say to the older people about how the quality of life of their residents can be improved.
- Eight of us voted that nursing and care homes should be a government responsibility and should be publicly funded. Two of us were against this and one of us abstained.

9. Drugs

- There should be better regulation of the drug company sales representatives in their dealings with the medical profession.
- Seven of us felt that it should not be possible for drug companies to extend the length of drug patents, as this slows the development of cheaper generic drugs. Three of us voted against this. One of us abstained.

10. Local Funding

- We support the kind of services provided by the Old Spice drama group and Rose Anne Kenny's falls clinic. They should be provided with appropriate funding. These services should become widespread.

11. Overall funding

- We think greater NHS funding is important to achieve these aims.

12. Research and Lobbying

- There should be more lobbying of the government to make them take notice and to act on the recommendations of research. Initiatives to prevent and reduce falls should have a particular priority as this will save money in the long run.

Jury's Concluding statement

Each person has different needs and problems and wants someone to genuinely listen to them. Care workers trained in older people's needs would be able to relate to that individual. They could inform doctors, social worker, the hospital, or a minister, priest or other religious leader. Many more care workers are needed. In the long term they can take pressure off doctors, hospitals, nurses and care homes. The initial cost would be considerable but it would be cheaper in the long term (e.g. reducing bed blocking).

It is in the individual older person's and the NHS's interest to positively promote and encourage independence among older people.

This will not be achieved by patronising older people by making them effectively immobile either by over-medication or by not allowing them the ability to move around. Such actions result in increasing feelings of vulnerability and lack of confidence, that lead to dependency and make recovery from a fall more difficult.

Verdict agreed 6 January 2003.

APPENDIX

Members of the Jury

(chosen at random from 6 wards in City of Newcastle)

Nancy Borchard
Philip Callaghan
Neil Chatterjee
Philip Donald
Nargis Haq
William Henderson
Philip Inglehearn
Natalie Lawrance
Rana Rafiqun Nessa
Karen Ritson
Muriel Sanderson
Nick Simpson
Connie Wallace

Witnesses

(provided evidence to jury hearings)

Nel McFadden, activist/researcher on older people's issues.
John Bond, Professor of Health Services Research.
Sheila Payne, Professor of Palliative Care.
Clive Ballard, Professor, Institute of Ageing and Health.
Rose Anne Kenny, Director of RVI Falls Clinic and Professor.
Vera Bolter, *Old Spice* Theatre Group and Elders Council,
Newcastle.
Nigel Baber, Medicines Control Agency.
Gary Ford, Consultant and Professor of Pharmacology of Old
Age.

Members of the Oversight Panel

(interested parties who will oversee the fairness of the process)¹

Claire Abley, Falls Coordinator, Newcastle NHS Trust
Sue Blennerhasset, Integrated Health Coordinator, Newcastle City Council
Vera Bolter, Newcastle Elders Council
Pamela Denham, Older People's Champion, Primary Care Trust, Newcastle NHS Trust
Barbara Douglas, Newcastle Healthy Cities Project
Sheila Gibbon, Alzheimer's Society, Newcastle
Julian Hughes, Consultant, Centre for the Health of the Elderly, Newcastle General Hospital
Tessa Harding, Director of Policy, Help the Aged UK, London
Graham Prestwich, Regional Manager, Pfizer plc²
Julie Tait, Age Concern Newcastle

DIY Jury Steering Group

(local older people who set up the jury)³

Jean Davies
Lorraine Hall
Eric Landau
Tony Mennell
Barrie Stott
Marjorie Taylor
Tom Walls
Bob Watson
Judith Williams
Mick Williams

PEALS Research Institute

(action-researchers co-ordinating the DIY Jury project)

Tom Wakeford
Fiona Hale
Tom Shakespeare

¹ Witnesses John Bond, Clive Ballard and Vera Bolter were also members of the Oversight Panel

² Also provided evidence in response to questions from the jury

³ The Steering Group was also advised by Professor Tom Kirkwood.

Dates of Jury Hearings

(held at Brunswick Methodist Hall, Brunswick Place, Newcastle)

2002: October (21, 28), November (4, 11, 18, 25),
December (2, 9).

2003: January 6.

Forthcoming PEALS publications

- *Teach Yourself Citizens Juries: A manual for planning, implementing, and campaigning with jury techniques.*
- *Video Handbook: How to set up a citizens jury (with Swingbridge Video).*

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