Building Leadership for Health

Leading Public Participation in Health

Notes for course leaders

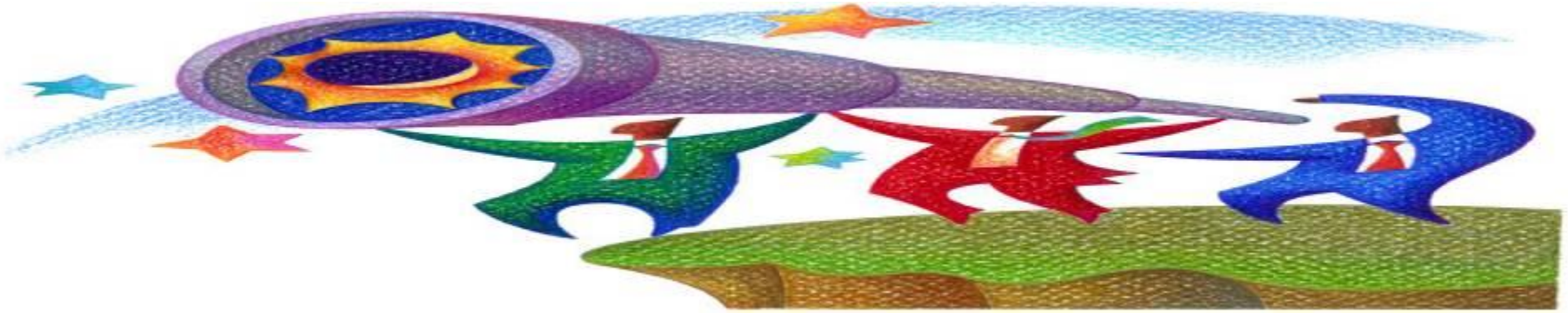
- Please develop your own course using this material. These are discussion points not lectures.
- As preparation please read Report of WHO Euro Health Futures Forum October 2005 this includes case studies from: Belgium, France, Germany, Portugal, Sweden and the Netherlands here
- You may also wish to read
  - “Purchasers as the Public’s Agent” Andre P den Exter Chapter 6 of Purchasing to Improve Health System Performance EHO 2005
  - Wide range of papers on PPI and its measurement (Google these)

Introduction and learning objectives

- What experience have you had in dealing with public participation in health policy?
  - What is your personal experience of engaging with national or local policy in other areas?
- The learning objective for the group is to
  - “To develop an understanding of current issues in patient and public involvement in health, examine and learn from the approaches to such issues in other countries and decide what to do next”.
  - What are your personal objectives.

Consider the long term future

- Why do you think public and patient participation is important?
- What trends do you see in the long term that would lead to greater or less patient and public participation in health policy decisions and personal choices for health



Long Term Health Future Trends

- Long term trends suggest:
  - Faster technological growth more possible cures
  - Higher survival rates from cancer, heart disease
  - But worsening lifestyles
    - obesity, diabetes, mental illness, tobacco
  - Longer lives but more long term health problems
  - Less informal care, more burden on health and care services unless community resources are used.
  - Increasing risk of pandemics due to zoonotic diseases and failure of antibiotics

Long Term Health Issues

- Health cost will continue to rise in real terms
  - Meanwhile dependency ratio will increase
    - Less people will be supporting more elderly and ill
  - Technology will offer cures at higher costs e.g.
    - Stem cell research and embryology
    - Genetic research and personalised medicines
    - Increasing use of online resources and devices
  - But health inequality is likely to continue to rise
- We cannot afford not to make choices in health and we can only make these choices with public and patient involvement - discuss.

Immediate issues

- **Just a few headlines from England at a time when health spending is rising**
  - **NHS rallies 'echo poll tax anger'**
  - **Marchers fight to keep hospital**
  - **Rally over hospital changes plan**
  - **Hospital protests over herceptin**
  - **Hospital staff protesting at cuts**

What does Public and Patient Involvement mean?

- What is a fully engaged health society?
  - Everyone has a say in health decisions?
  - People make individual health choices?
  - More consultation with special interest groups?
  - A social movement for health*?
  - People are co-producers of health?
- Discuss what you mean by
  - Patient and public involvement?
  - In what sort of decisions?
  - What are the advantages and disadvantages?

*See paper on social movement theory in health here

Participation in health: basic concepts

- **Voice**: articulating opinions and perspectives
- **Representation**: formal ongoing role in decisions
- **Choice**: individual right to decide on treatment
- **Patient rights**: a legal basis for voice, representation and choice and information

Voice

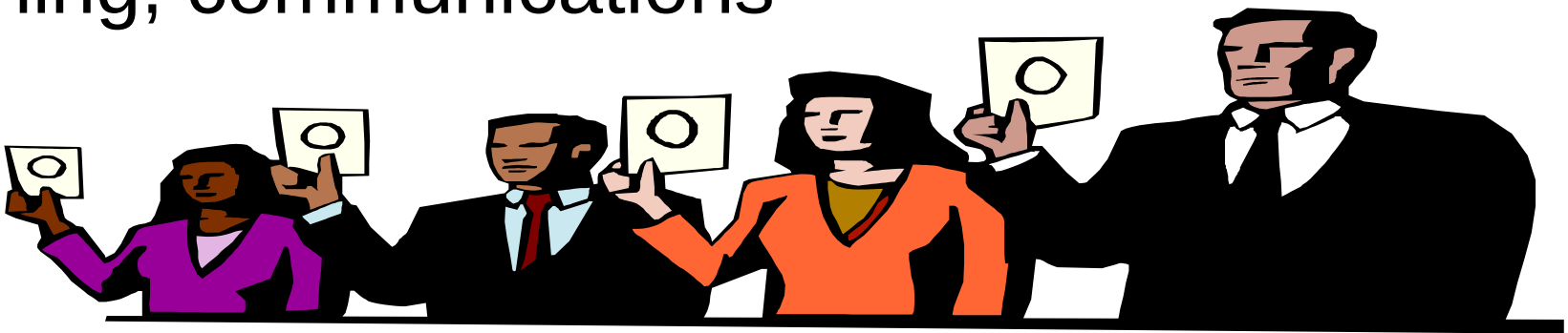
- Voice: articulating opinions and perspectives
- Legitimacy: experience and perspective
- Techniques: surveys, feedback, focus groups, consumer panels, patient or citizen juries, public patient forums, hard to reach groups
- Consumer Power depends on: agenda setting transparency, information, links to community, skills of participants, listening culture.

Voice brings recognition and healing

- We all belong to minorities
  - Who is not from an ethnic minority or from a minority religion or has no particular health problems?
- We are all minorities and with no voice
  - We feel isolated, undervalued and lack confidence
- Voice gives recognition
  - Gives value, creates community and gives power
- Giving voice can be a healing process
  - Empowering us as citizens and as patients
- But it does not replace representation or choice

Representation

- Representation: formal ongoing decision role
- Legitimacy: elected or nominated by local council, or patient/consumer org
- Structures: Health agency board membership, council committee
- Power: links to local communities, information, training, communications



Representation makes power possible

- Having locally elected representatives means
  - It is possible to take communal choices and to respond to local voices
- But it does not ensure either
  - Elected representatives may have limited choices
  - They may have poor information and
  - May lack ways of listening to local minorities

Representative Patient Juries

- Groups drawn from general patient/public
- Sometimes provided with basic training
- Case for and against action is presented
- They question experts and decide
- Used for
  - Examining reform proposals
  - Health care priority setting and rationing
  - Health planning decisions
- Read article here
  - And discuss advantages and disadvantages

Choice

- Choice: ability to select from alternatives
- Legitimacy: available options, insurance conditions, affordability.
- Extent of choice: GP, provider, treatment, public/private sector, insurer, opt out – individual and community choice
- Power: individuals vote with their feet, to define the service they want – community choice requires representation and voice

Choice is not easy for everyone

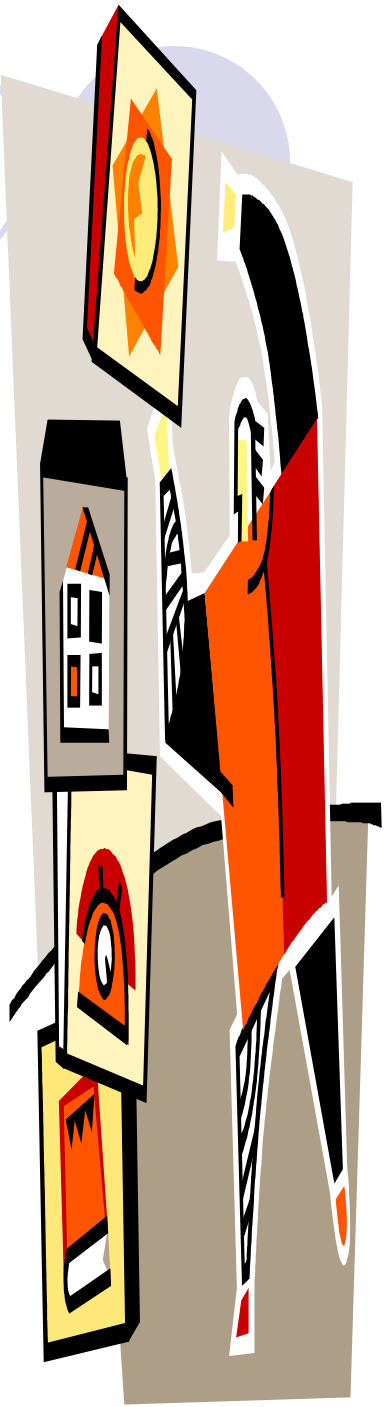
- Choice gives power but
  - Who decides what choices will be offered
  - How are voices and representatives engaged
- Choice can widen inequity
  - Less disadvantaged will be better at choosing
  - Better informed and more able to afford options
- Choice needs to be supported by
  - Action to reach disadvantaged
  - Voice and Representation

Patient Rights

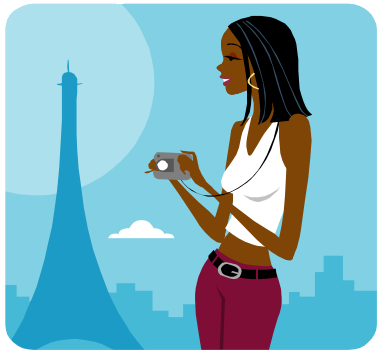
- Patient rights: legal basis for claims on system
- Legal base: European Bill of Patient Rights, National Consumer /Health Law Patient Charter
- Power: patient information, advocacy, duty of providers, ombudsperson, community links
  - Patient rights underpin the culture for voice, representation and choice

Team Review: Current approaches to PPI

- Each team member review one case (read report here and see following slides)
  - France
  - Germany
  - Sweden
  - Belgium
  - Portugal
  - UK
- Discuss the differences and similarities between current approaches to PPI
- Are there any common lessons

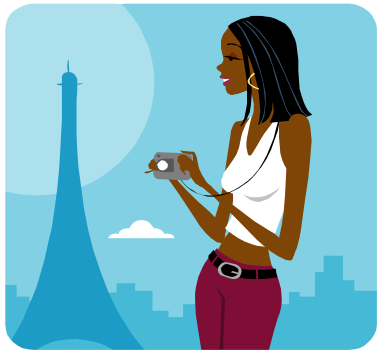


France



- National social insurance schemes
- Schemes heavily indebted/underfunded
- Choice of add on insurance and providers but better providers charge higher fees
- French system “best in world” - WHO
- But heading towards greater inequity
- And unsustainable costs

France 1998-2004 National Consultation



- Jospin commitment to public involvement
- 1998 National Consultation
  - 1000 events in 180 cities = 200,000 people
  - Supported by expert panels and media debate
- Brave and ultimately useful but
  - No consensus on reimbursement of 221 products
  - Decision taken by politicians 6 years later
- Led to patient rights legislation and increased role of patients on health bodies

The Netherlands

- Patient/public rights backed by law
- Patient choice of health insurer and provider
- High levels of public involvement (17%)
- National Patient Consumer Federation
- Consumer advocacy locally and nationally
- But lack of competition and choice for poor
- Only higher income groups free to choose different forms of insurance

The Netherlands 2006 Patient Choice of Insurance

- Reform to extend choice of benefits package
- Open competition in health insurance
- Benefits package options at standard price
- NPCF - consultation and monitoring but
- No clear consensus on impact on equity
- May lead to less evidence based decisions
- Decision made at political level

Germany

- Federal and regionally managed system
- Choice of insurer and provider but
- Standard insurance benefit package
- With some minor variations
- Few actually exercise choice of insurer
- Consumers/patients not well represented
- Historically they have been adversarial

Germany 2004-2006 Competition and Choice

- Greater competition in insurance market
- Additional choices and co-payments with exemptions to address equity issues e. g.
  - Higher co-payment for self referral to specialists
  - Bonuses for enrolment in disease management
  - Pay-backs for enrolment on prevention programs
- Stronger voice for patients/consumers on
  - Joint Committee of Sickness Funds, Doctors and Hospitals (though without voting powers)
  - Introduction of stronger ombudsman

Sweden

- National, county and local policy decisions
  - Elected representatives at each level
  - User councils, citizen dialogues, study groups
  - Pilots of patient/consumers on hospital boards
- Largely tax funded insurance scheme
- Limited choice of hospital provider based on waiting times and priorities.
- Priority setting is ongoing part of system

Sweden 1993-2006 Health Priorities

- National consultation on health ethics 1993-95
  - Principles established: human dignity, recognition of needs and solidarity, and cost-efficiency but not public choice, social disadvantage or age
  - 5 groups: life threatening, severe chronic, prevention and rehabilitation, less severe, borderline, other care
- Implementation Committee 1998-2006
  - Technical appraisal of “horizontal” and “vertical” priorities,
  - Still ongoing to guide resource allocation and waiting times
  - Process is transparent and consumers are informed and consulted but not really involved in detailed decisions

Belgium

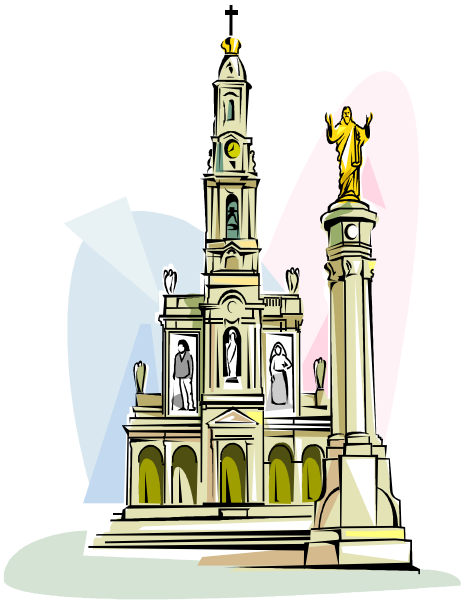
- Federally managed system
- Social insurance largely not for profit providers
- Choice of insurer and providers
- Patient oriented, whole person approach
- Local and regional health promotion focus
- Aim to achieve better balance between patients/consumers health care providers and managers

Belgium 2002 Patient Rights

- Patient Rights Act to improve patient focus
  - Rights to: high-quality care; choice of provider; information on health status; informed consent***;*** access to medical records, protection of privacy and the right to complain to the ombuds function.
  - Established Patient Rights Commission working with local ombuds offices to support patient rights and input to national policy through annual reports and consultations
- Modified by consultation to include:
  - separate laws on patient rights, direct access to medical records, support for those unable to exercise rights.

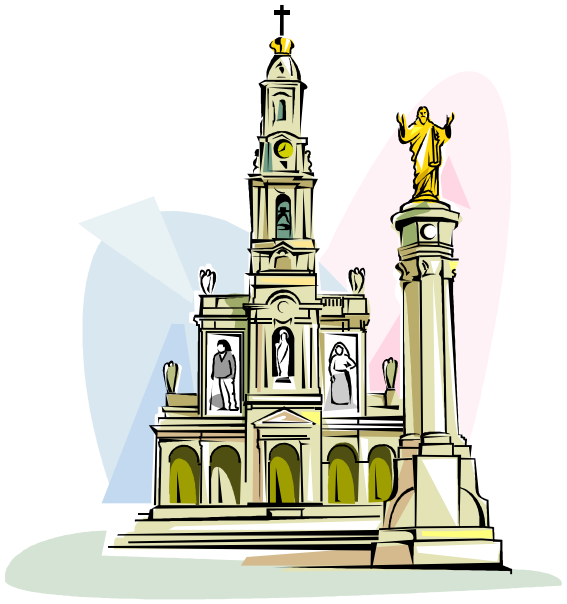
Portugal

- A National Health System free at point of use
- Managed through 5 Health Regions
- Public and private sector insurance /provision
- PFI schemes and Public Enterprise Hospitals
- Longstanding problems
  - Quality
  - Cost effectiveness
  - Lack of patient centred integrated care
- 1999 plan fails
  - due to lack of involvement



Portugal 2002-2006 National Strategic Planning

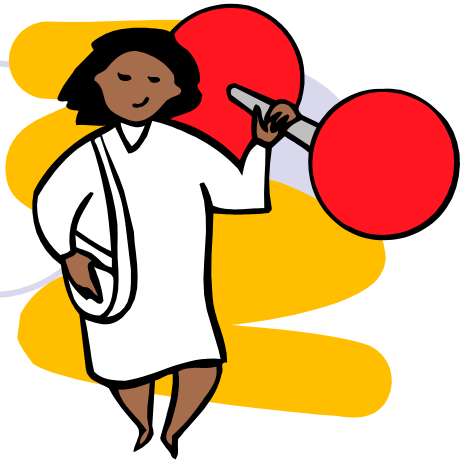
- New strategic planning process
  - 2002- 2004 - objectives, targets and guidelines
  - 2004- 2006 – launch, structures and resources
  - 2006-2010 – implementation and monitoring
- 614 responses invited but only 108 received
- Public consultation meetings but
- Consensus not clear
- Involvement now built in to plan
- Useful even if not decisive



PPI to transform English NHS 2003

- Patients voice in NICE decisions on policy
- Patients on purchaser/ provider boards
- Foundation Trusts elect patient board members, elected councils exercise oversight
- Patient Public Forums for each purchaser/provider
- Advice and complaints advocacy services
- Patient choice of 4-5 hospitals
- But culture slow to change
- Systems too complex and rigid
- Too little democratic representation
- Or engagement with communities

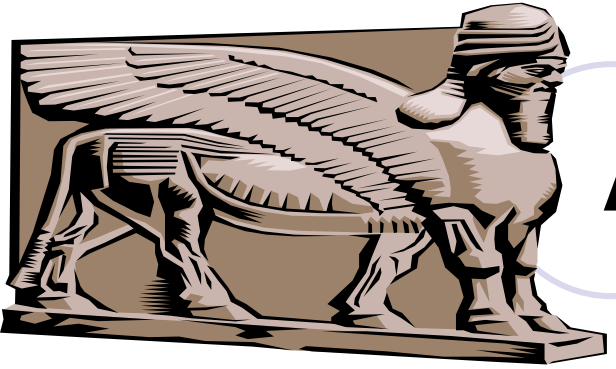
A Stronger Local Voice in England 2003



- After only three years approach to PPI changed
- Local Involvement Networks replace Forums
- Commission for Patient and Public Involvement replaced by academic centre and network body
- Stronger role in regulation and local Council Oversight and Scrutiny Committees
- Legal duty of NHS bodies to consult strengthened

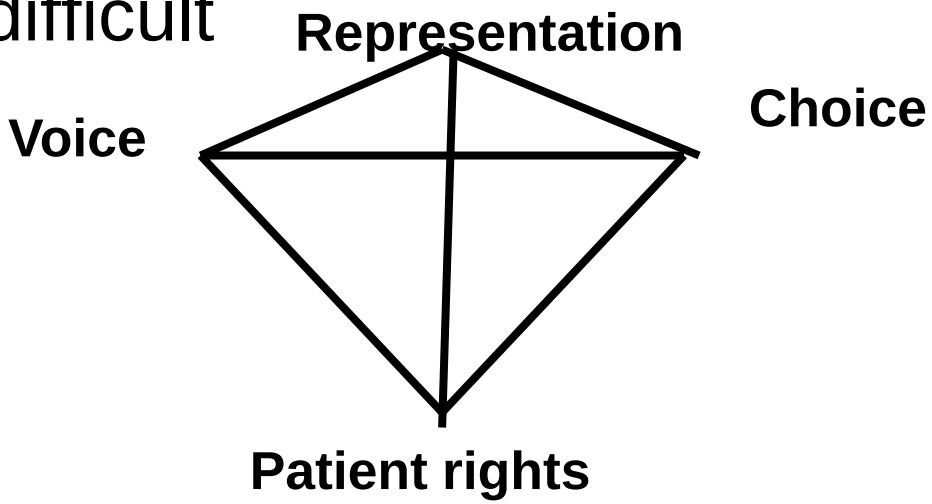
Lesson from European experience

- Consider the following general lessons as a basis for your own case study
  - You need a strategy for involvement with a
  - Balanced approach to voice, choice and representation
  - Clear organisation and rights
  - Good practical information for citizens
  - Careful timing of consultation and decision making
  - Respect for individuals as co-producers of health



A Strategy for Involvement

- Voice, representation, choice are complementary
- All three elements are required for involvement
- Creating a culture of listening and respect
- Supported by advocacy and patient rights
- These processes are difficult
- And uncertain but
- Essential

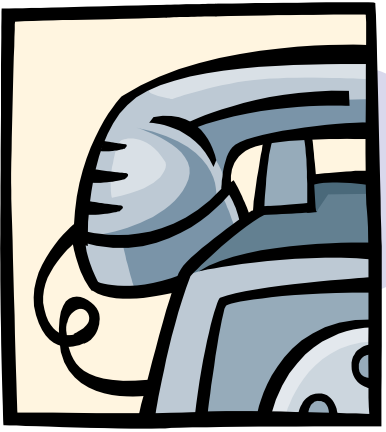


Voice needs organisation

- Networks not command and control
- Owned by consumer/ patient organisations
- Providing support
  - Training, research and support
  - Advocacy and action on complaints
  - Ensuring p/p organisations are involved
- But not creating false/forced consensus

Need for clear rights and duties

- Rights of citizens need to be matched by
- Duties to involve and consult but also the
- Duties of agencies/professionals to take decisions
- As choices become wider and more complex
- It is more important to be clear about the rules



Informed choice

- Requires not just information
- But education, advice and support to enable
- People to make informed choices
- Both at individual level and
- For collective decisions

Timing

- The nature of involvement depends on timing
  - Voice indicates general attitudes and needs
  - Representation involves communities in decisions
  - Choice is selection from a set of options
- And is a product of culture
  - Consultation with a limited set of agencies
  - Was real progress in Portugal
  - A common mistake is to consult after the decision
  - On the grounds that you know what people will say
  - You don’t !!

Respect the whole person

- People are not just “Patients” or “Clients”
- But consumers of public and private services
- Shared owners of public services
- Co-producers of health and care
- Health/ Care are some of many life choices
- Services must be built around personal
- And collective informed choices

PPI : Case Study

- Your team is asked to prepare a strategy for Public and Private Involvement on decisions concerning the future of hospice care.
  - Consider voice, representation, choice and patient rights
  - Decide how/ when to consult the public?
  - Prepare headings for a consultation document
- Hold a town hall meeting to get public views
  - The rest of the participants will be patients and public

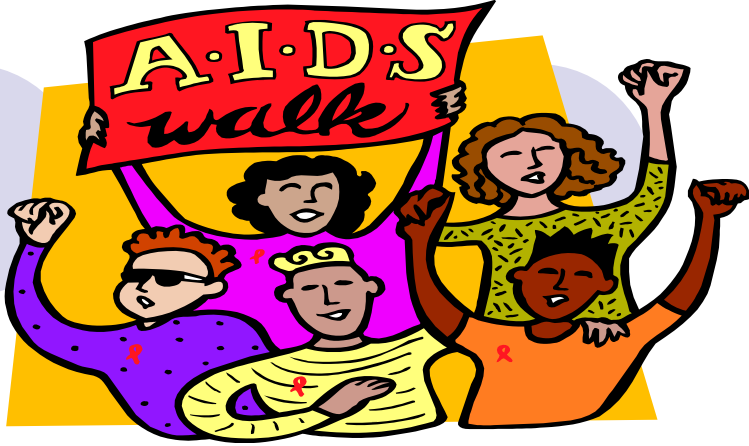
Note to course leaders

- You need to identify an unpopular/difficult decision
  - As examples closure of a local accident and emergency centre because experts think that a central service would be better or
  - Replacement of a maternity ward because experts think that the current unit is not capable of meeting modern standards or
  - A decision whether to fund hospice care, because budgets have to be cut and this is a non statutory requirement.
- Get the group to think through the decision to be made – under what circumstances would they take different decisions.
- Get them to think about the nature of the decision (not the outcome) before they decide how to consult

PPI : Case Study lessons

- It is crucial to match the process to the nature of the decision
- As a minimum to ensure
  - You thought about who to involve
  - You involved them at the right time
  - You shared knowledge with them openly
  - You listened to their views
  - You took views into account in any action
  - You explained why and how you took a decision

Fully Engaged Society



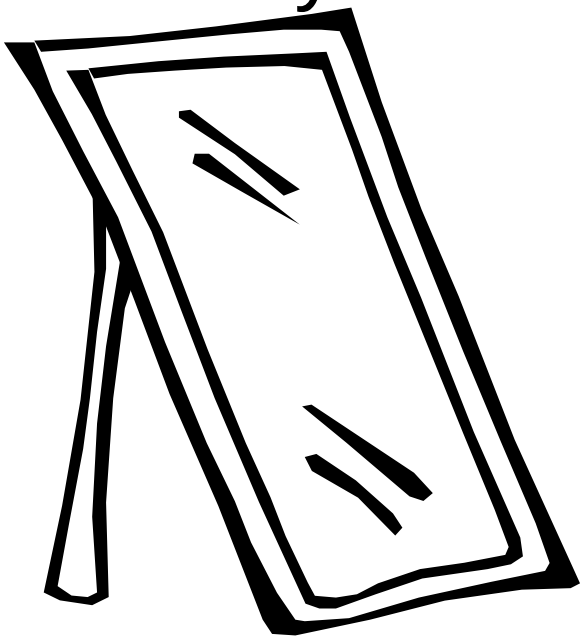
- Health is everyone's responsibility
  - The state: setting policies for health, determining responsibilities, regulating the system, managing resources, leading ethical debates.
  - Public and patient: responsible for their health, knowledgeable about health, co-producers of health, and owners of health and care insurance.
  - All sectors of the economy: employers, producers, retailers, teachers, health workers

Lessons from Experience :Discussion

- What lessons do you draw from experience
  - Is your system trying to increase PPI?
  - What are the main means of doing this?
  - Are you succeeding?
  - What problems are you finding?

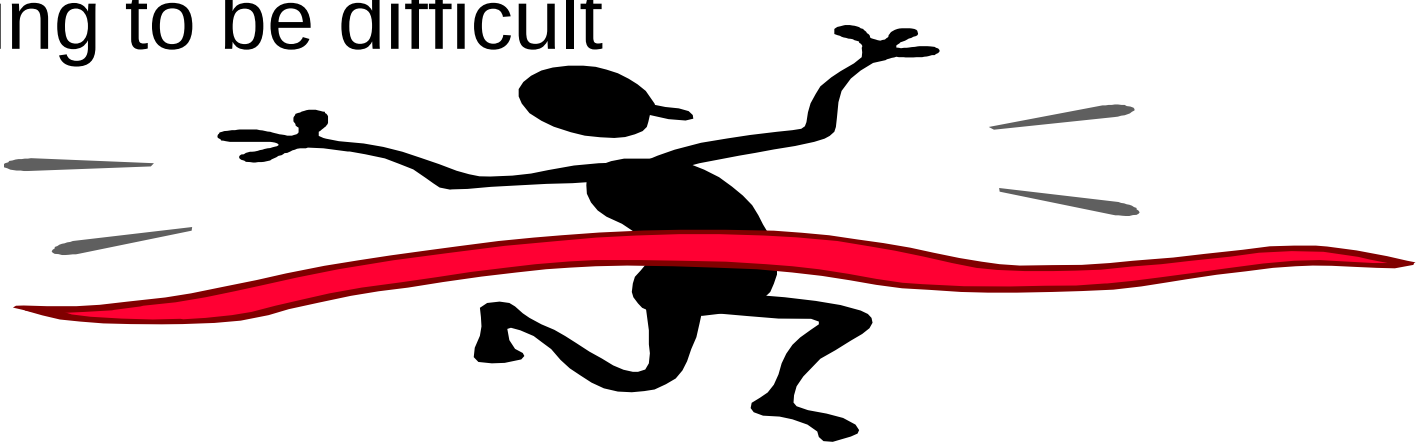
Reflections and Feedback

- What conclusions do you draw?
- What have you learnt from this session?
- Is this relevant to your system?
- What will you do differently?



Conclusions

- Future will bring need for more participation
- All systems have voice/ representation/ choice + patient rights - its a question of degree
- What works depends on culture + commitment
- It requires long term multi level action
- Goal is transformation to fully engaged society
- But it is going to be difficult



Course contributed by Graham Lister

- Graham was the health consulting partner for Coopers & Lybrand the largest group in the UK at the time.
- He later became Chair of the College of Health, a national patient organisation and made many speeches on the topic of patient and public involvement.
- His intervention was a factor in the establishment of the Commission for Patient and Public Involvement in Health.
- He was also senior associate of the Nuffield Trust and led their work on patient involvement.
- He is now senior associate of the Judge Business School, in this capacity he assisted the WHO Euro Health Futures Forum to examine this topic.
- He is also visiting professor at the Centre for Leadership and innovation at the Health and Social Care Dept of LSBU