



Southern Institute for Health Informatics 2015

Personalised health and care by 2020?

# **Providing information for patients and carers to enhance shared decision-making**

## **...illusion or reality?**

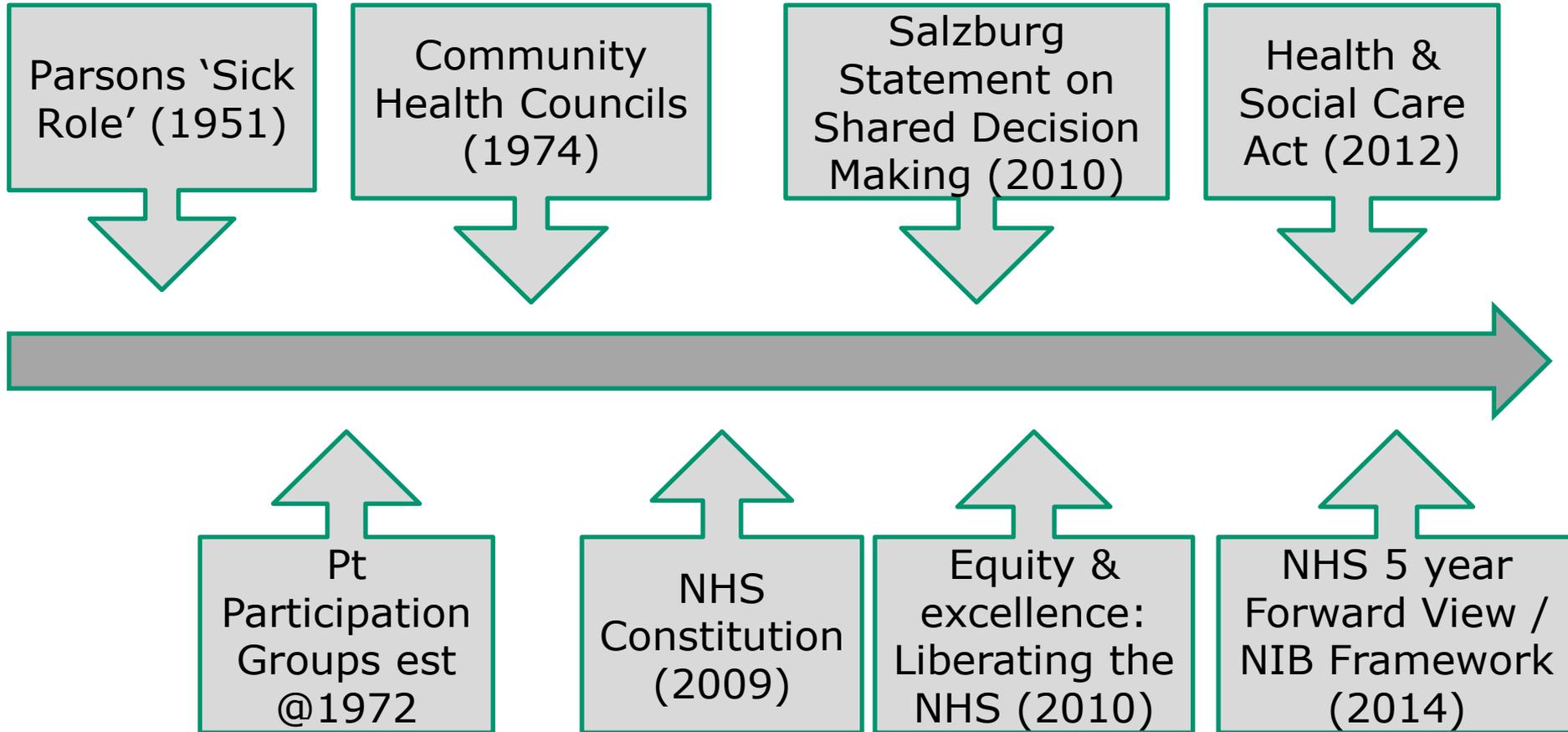
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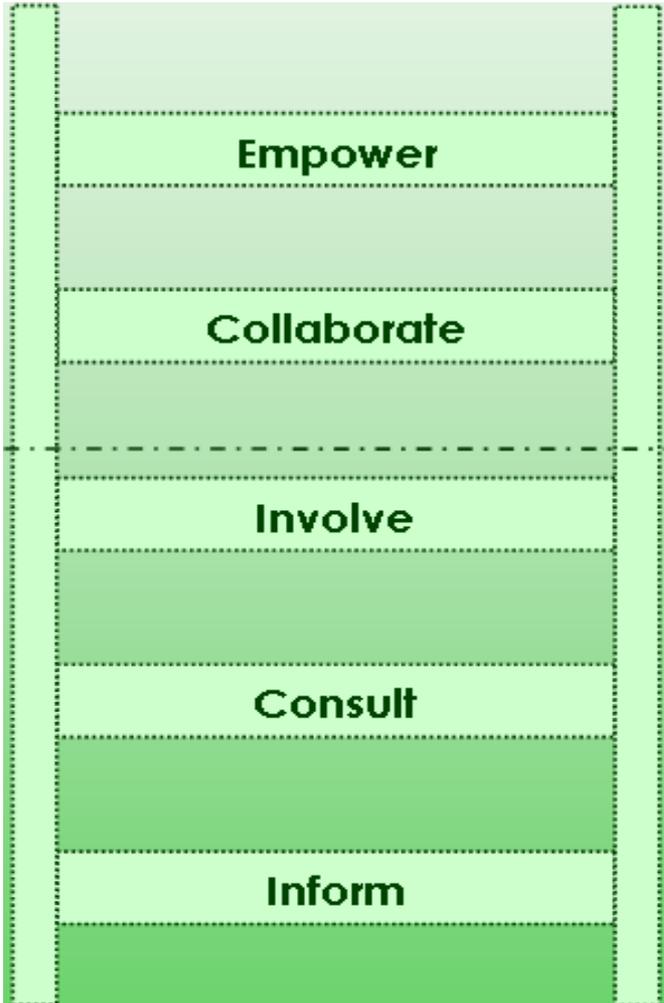
## ***'No decision about me without me'***



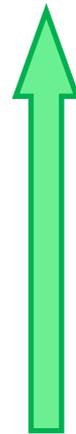


# What is Involvement?

IAPP  
Spectrum of  
Public Participation  
(2000)



High level of involvement;  
2-way information and opinions  
Shared decision making



Involvement:

- at an individual level
- at a collective level

Low level of involvement;  
Paternalistic; professionals providing  
their opinion



## Shared Decision Making

*‘Clinicians and patients working together to clarify treatment, management or self management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action’*

- The aim is to support people with long term conditions and their carers to become:
  - Informed
  - Empowered
  - Activated
- Hours spent with professional = approx 3 per year; hours spent self-caring = 8757 per year
- NB - Accessing those who are seldom heard or seen



## ***'I am not "hard to reach"... people don't know how to reach me'***

- 'Hard to reach' ...by whom?
- Not the fault of the non service-user; certain groups or individuals are being excluded and this is the fault of the services themselves
- Many barriers, eg: previous poor experiences, location and opening times of services, low levels of health literacy
- Key areas to address:
  - attitude of staff; empowering users to be involved
  - service flexibility;
  - working in partnership with other organisations
  - easily accessible information



# Where is the information?



self  
management uk

iWantGreatCare



National Voices



People shaping health and social care



Stroke  
association



The NHS  
non-emergency  
number

healthwatch



healthtalkonline



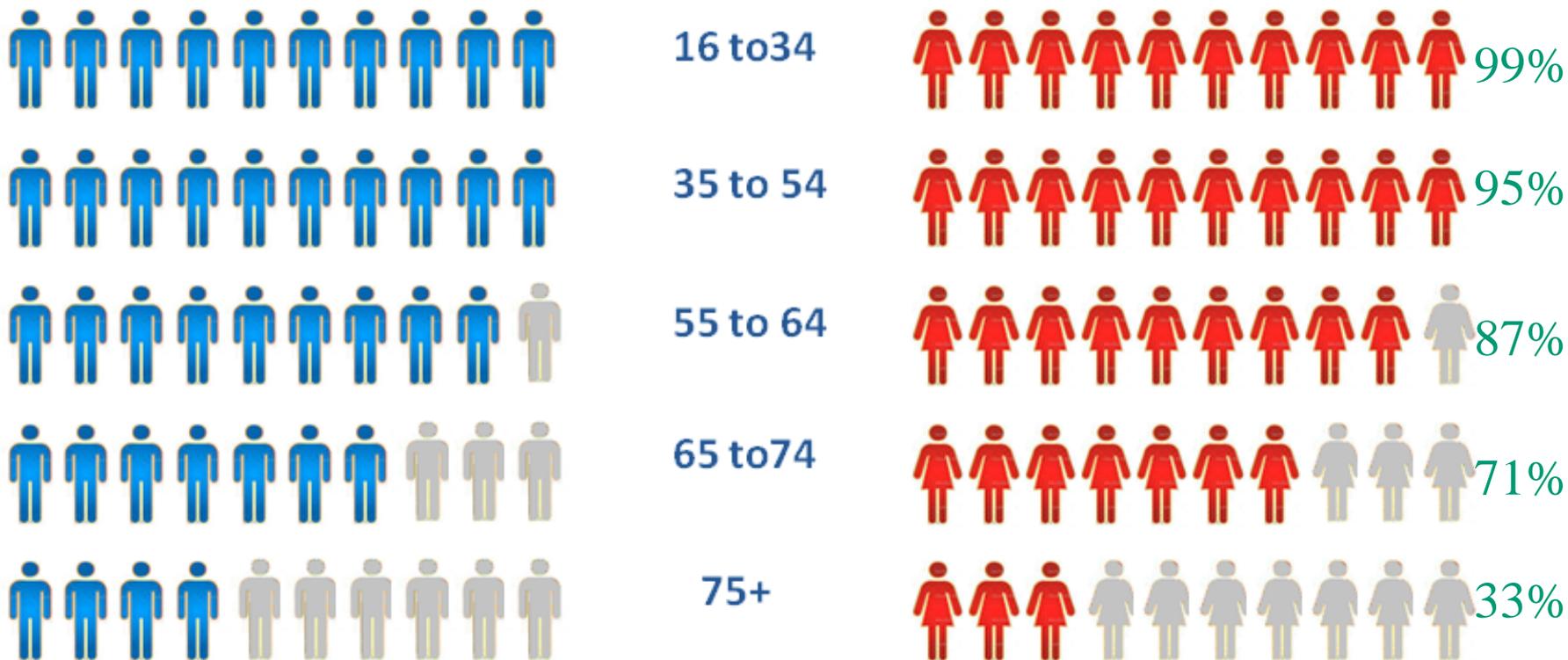
- However...it's not always easy to find
  - if people don't know what to look for or where to find it
  - for those without internet access

# Recent internet users by sex and age group, quarter 1 (Jan to Mar) 2015



Almost 9 in every 10 adults in the UK have used the internet in the last three months (86%)

Almost all men and women aged 16 to 54 years have used the internet in the last three months ...



..but just 4 in every 10 men and 3 in every 10 women aged 75+ have used the internet in the last three months.



## Do patients feel involved and empowered?

- Despite the emphasis on empowerment, patients still do not feel sufficiently involved and empowered
- My research: ‘How effectively can CCGs meet requirements to involve and engage with patients with long term conditions?’
- The Patients Association (2012) survey; patients reported:
  - Feeling disempowered and disengaged from their care
  - Wanting to be better supported to manage their conditions independently
  - 80% wanted to be more involved in decisions about planning their care and treatment



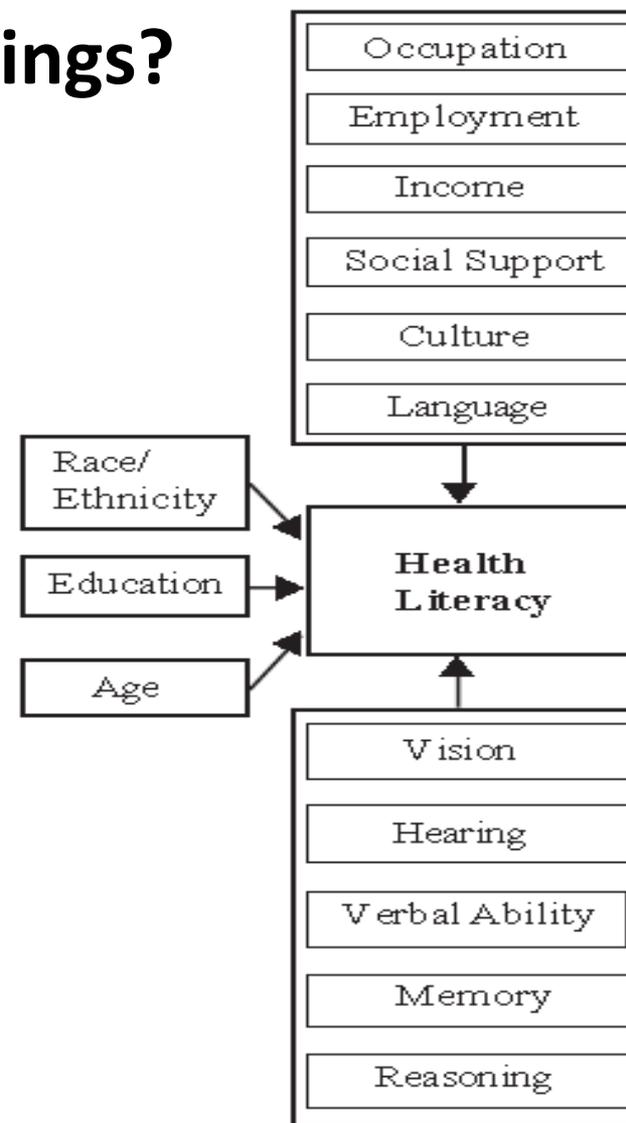
## *...illusion or reality?*

- 85% of clinicians believe they share decisions about treatment with patients
- 50% of patients believe this is the case (Blakeman, 2004)
- IPPR, 2014 – surveyed over 2,500 people with LTCs
  - 7% had been offered peer support; 9% had been offered education
  - 11% had been offered information about local services & support
  - 40% had been offered information about their condition
  - 53% of respondents had been offered nothing
- Accenture Life Sciences 2015 – surveyed 10,000 patients across 5 countries; UK results (n = 2000):
  - 83% of patients are not aware of services available to them
  - Once patients were aware of services
    - 59% accessed these services
    - 74% accessed information about their condition



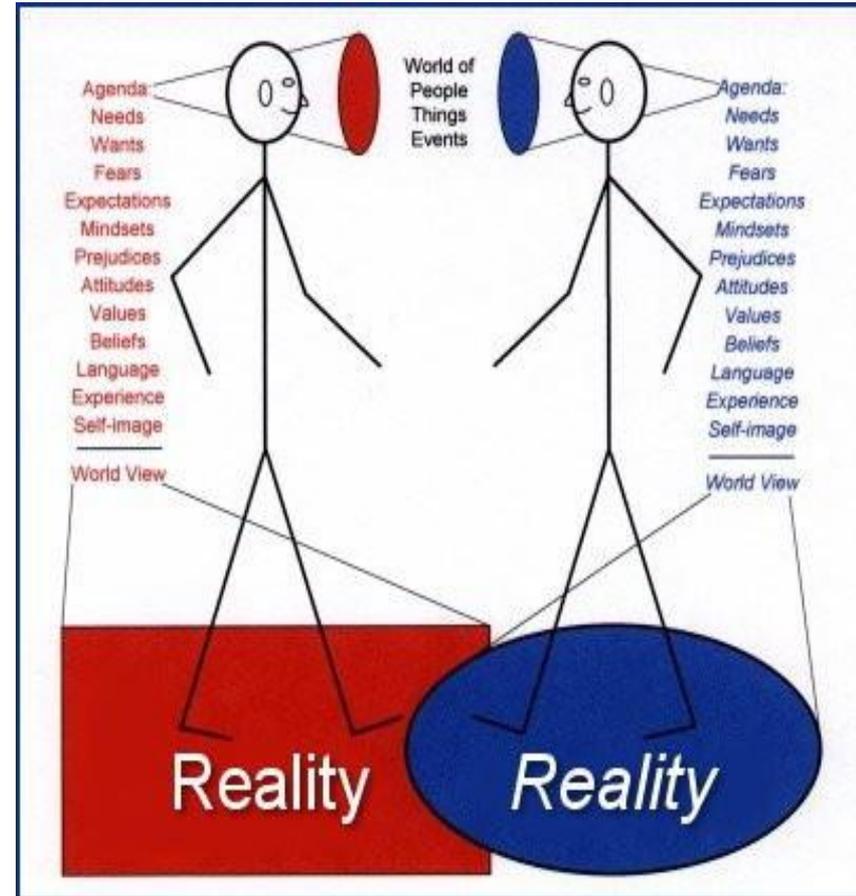
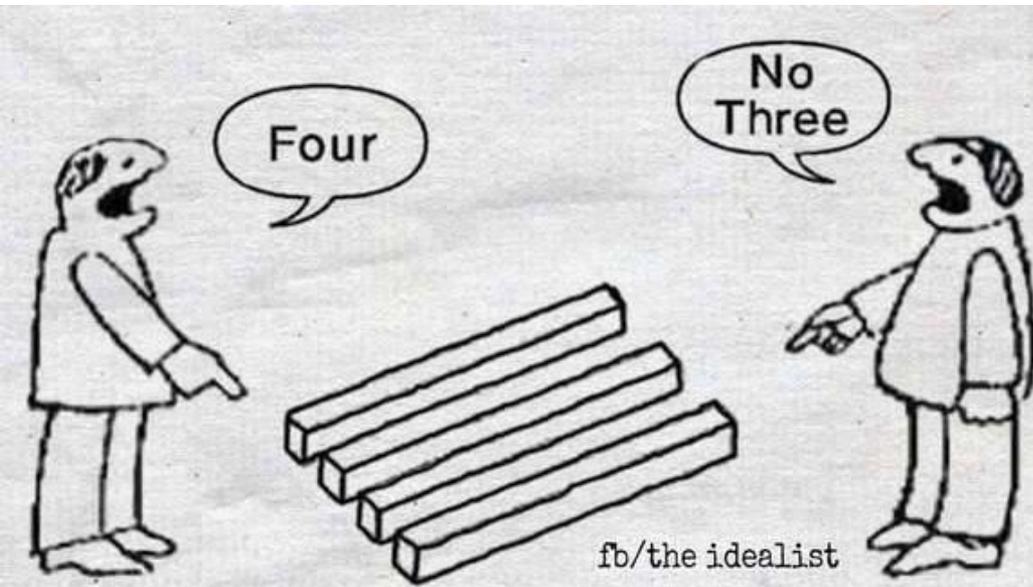
## What might explain the findings?

- Health Literacy impacts on people's ability to navigate the healthcare system, share personal information, (eg symptoms), and manage their own health
- 43 % of people aged 16 – 65 are unable to effectively understand and use health information...but they may not realise they've misunderstood
- Skills for Life survey (2011); 15 % (5.1 million) English adults have literacy skills below level 1





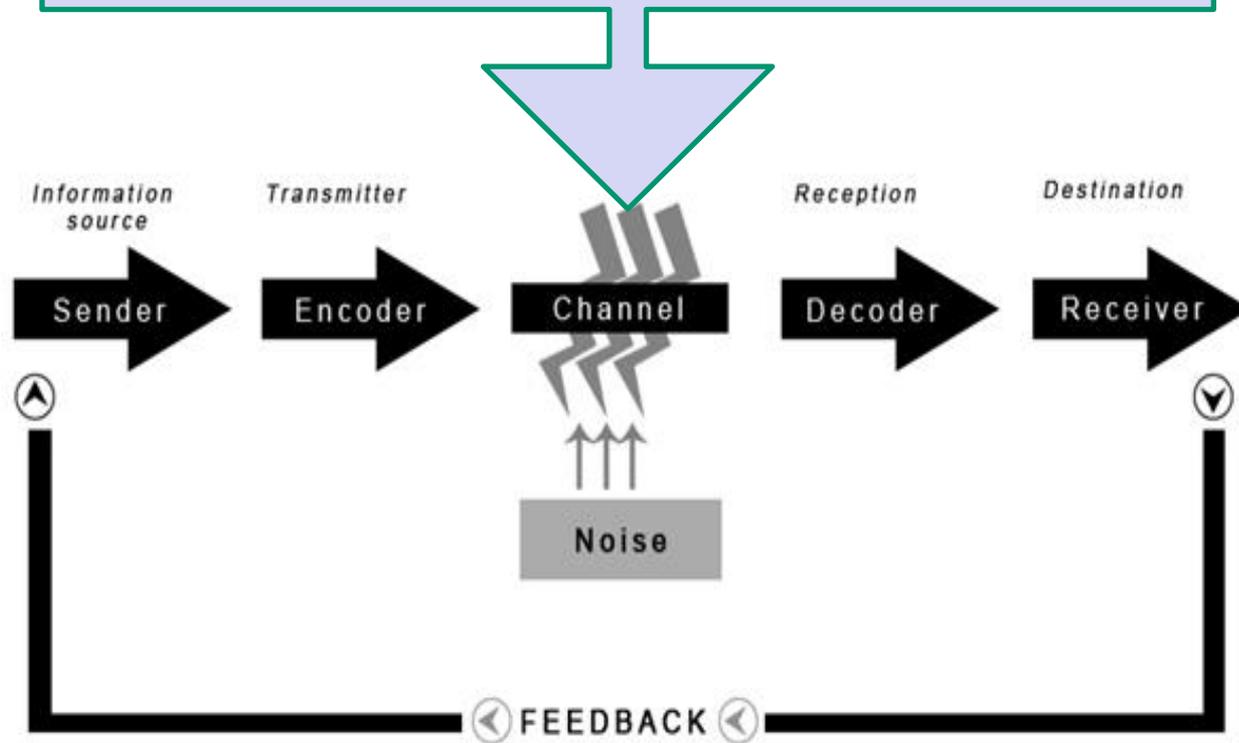
## Differing perceptions



How might people's outlook on life affect communication?



- Experience of illness
- Social circumstances
- Differing perceptions
- Patients unaware of treatment or management options
- Clinicians unaware of patients circumstances & preferences
- Level of activation



Shannon-Weaver  
Model of  
Communication (1948)

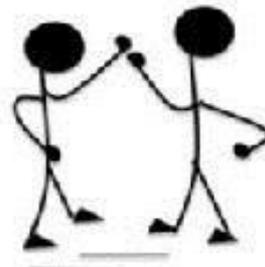


## Improving information provision

- Provision of information needs to be integrated into healthcare pathways so patients can easily access high quality health information \* *relevant and appropriate for them*\* at every step of their journey
- Patients need to be supported to build the knowledge, skills and capacity for shared, and informed, decision making
- Information provision must take into account people's social, emotional and practical, as well as clinical needs
- Focus on strengthening people's capabilities so they are
  - less dependent on services
  - better able to manage their condition themselves and
  - able to maximise their well being and level of independence



Tell me and I forget. Teach me  
and I remember. Involve me  
and I learn.



- Benjamin Franklin

Thank you