



# Goal setting in MS

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# Shared decision making

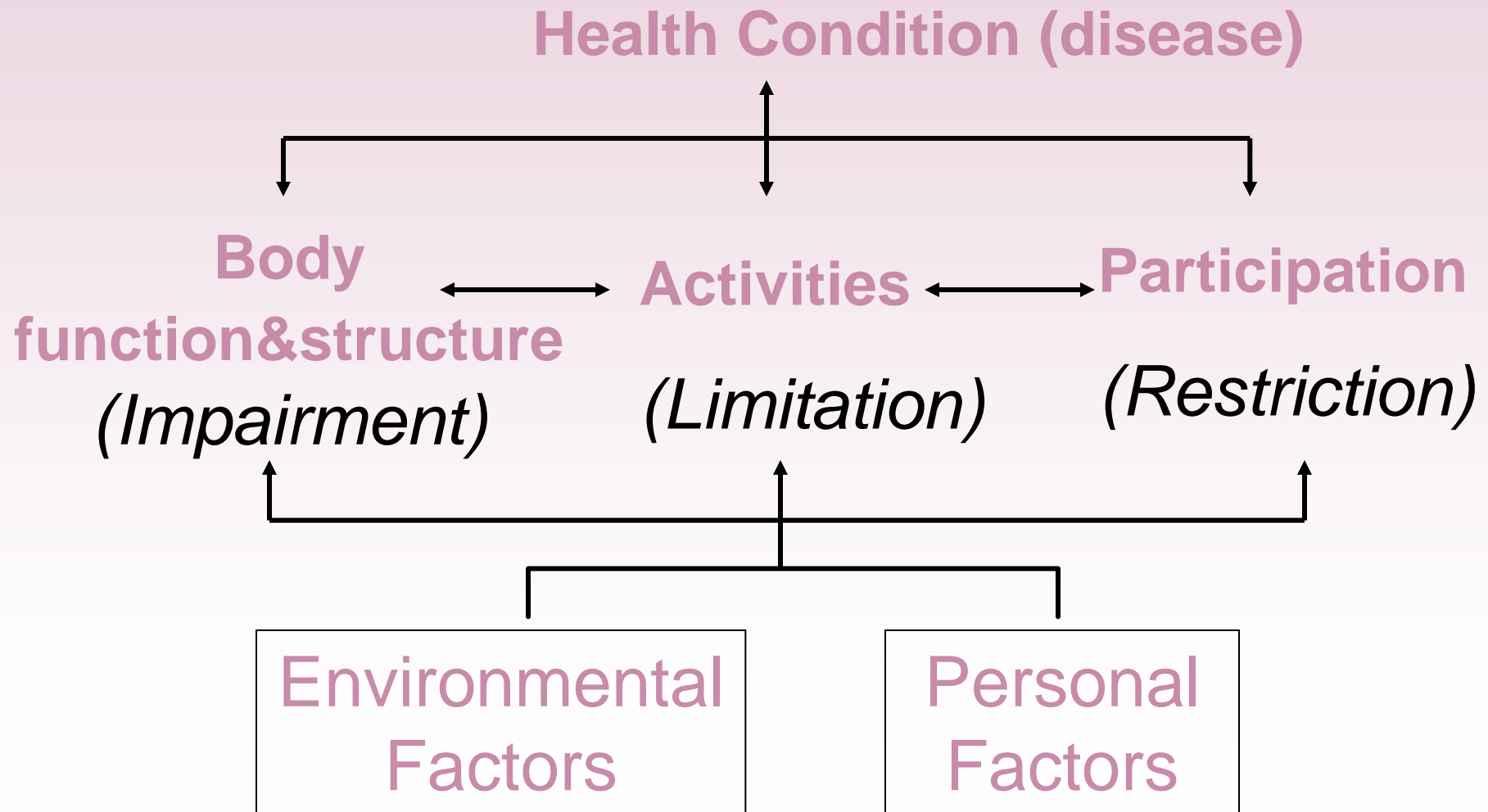
Coulter and Collins

- is appropriate in every clinical conversation where a decision point has been reached and where the situation is not immediately life threatening,
- self management.
- personalised care planning,
- do not identify goal setting or rehabilitation as environments in which shared decision making takes place.

## Goal setting

A process of discussion and negotiation in which the patient and staff determine the key priorities for that individual and agree the performance level to be attained by the patient for defined activities within a specified time frame.

# Interaction of Concepts - ICF 2001



## SDM and the ICF

- Shared decision making means exploring patients knowledge, understanding, values, preferences and beliefs, as well as an accurate understanding of the underlying impairments, activity limitations, participation restrictions and environmental factors.



## Goal setting as SDM

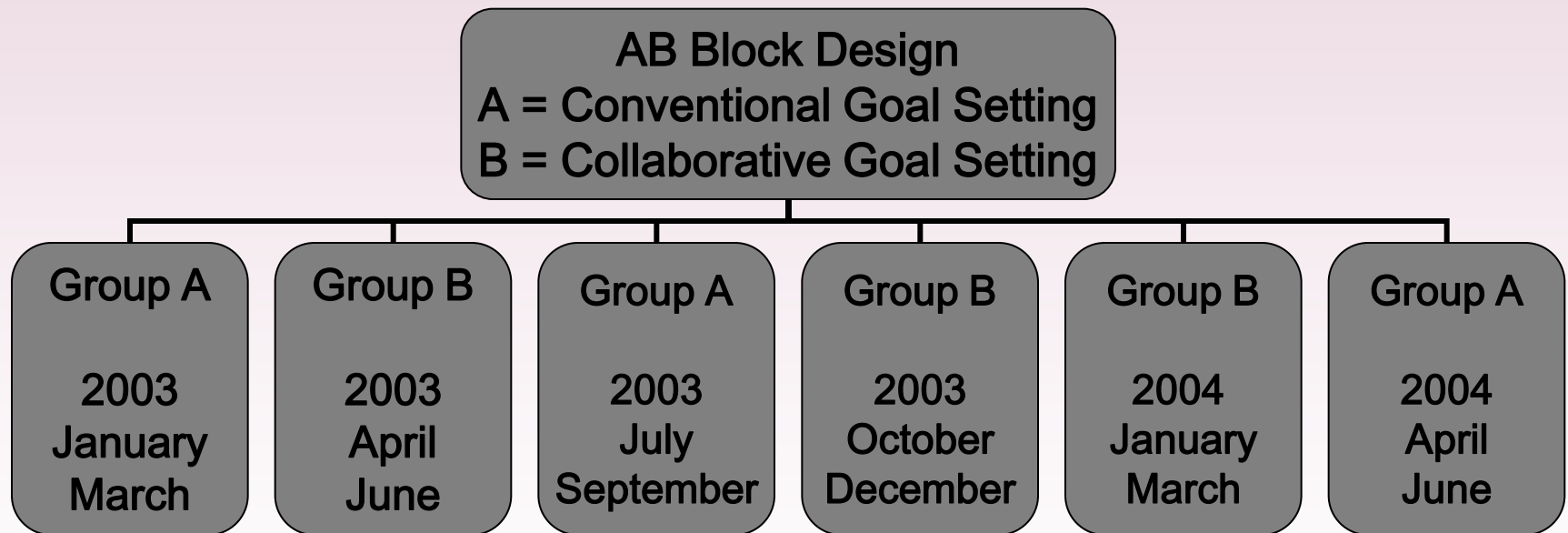
- working with the patient to identify the goal core.
- considering different routes to achieve that goal core; each may require the acquisition of different knowledge, skills, and attitudes and each may have different risks.
- clinician then needs to work with the patient to see which route fits best with their underlying values, and beliefs.







# Study Design



## Group A

### Conventional

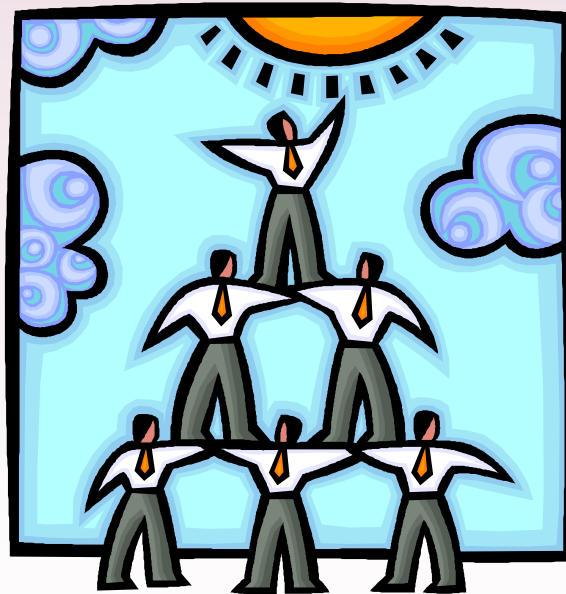
- Joint assessment
  - PT, OT, RN, SALT
  - Aims of admission
- 5 day assessment period
- Long term and short term goals set
- Presented to the patient

## Group B

### Increased participation

- Goal setting pack
- Key worker interview
- Participation in goal setting meetings
  - Set goals
  - Review goals
  - Discuss attainment

# Goal Setting Pack



Prior to admission

1. Prioritise 6 cards
2. Specify tasks from priority 1-3 cards
3. Break down
4. Goal formulation with Key Worker

# Key worker interview

- I'd like to understand a little more about the main difficulties your condition is causing you at the moment. Please could you tell me what these are?
- Are these difficulties affecting your key roles or responsibilities?
- Have these difficulties had an impact on your mood or levels of worry?
- Which of your roles/responsibilities are going well?
- What is your long term hope for your everyday life?
- What are you expecting to achieve during this admission?
- What are your strengths that you think will help you during this admission?
- What do you think may be unhelpful?
- What do you feel the people around you expect from rehab?
- And what do you feel they expect from you?

# International Patient Decision Aids Standards Collaboration

Choice:

Decision process:

- recognize that a decision needs to be made;
- know the options and their features;
- understand that values affect the decision;
- be clear about the factors that matter most;
- discuss values with their practitioner;
- become involved in their preferred ways.

# Outcomes

Relevance

Perceived participation/autonomy

Functional outcomes

Resource implications



# Outcomes

## Relevance

Goal visual analogue scale  $p < 0.000$

5 point scale  $p < 0.001$

## Perceived participation/autonomy

4 point scale  $p < 0.0001$

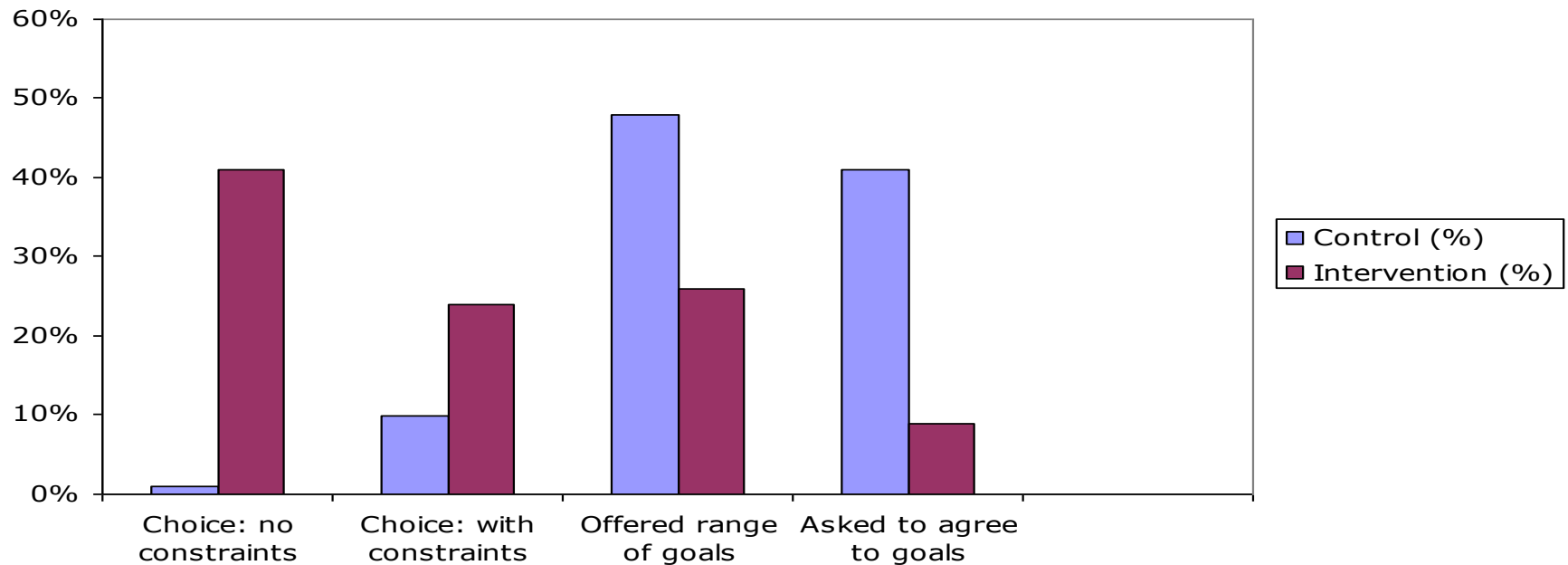
## Functional outcomes

FIM, London Handicap Scale NSD

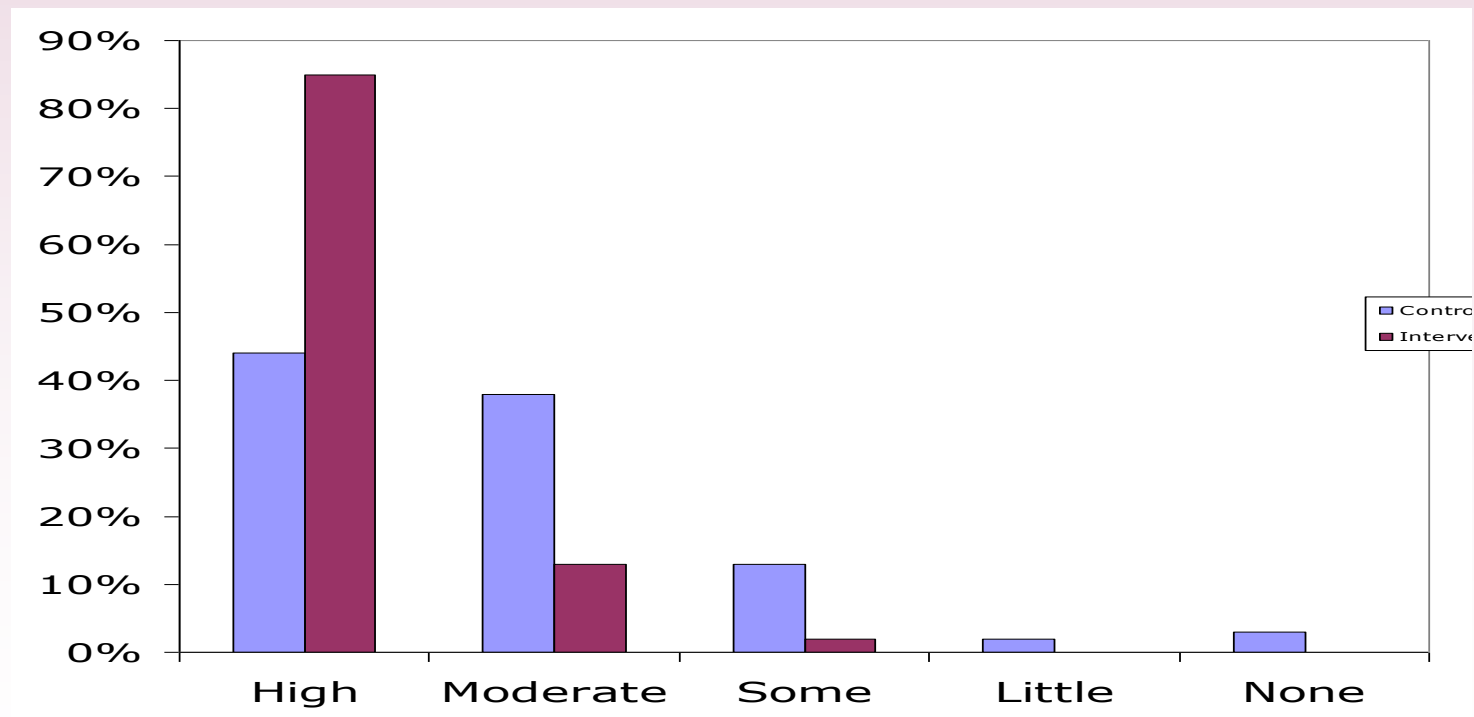
## Resource implications

Length of stay                      NSD

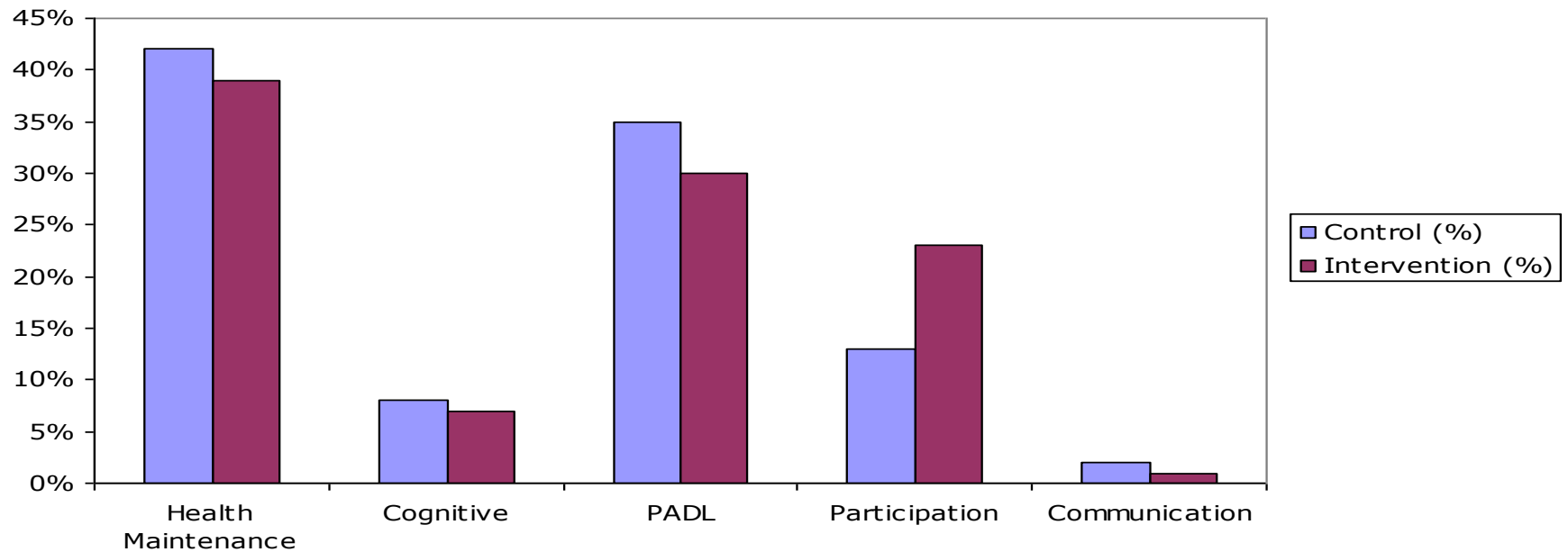
# Patients perception of involvement



# Goal relevance



# Goal components



## Summary

Patients involved in the goal setting process experience greater autonomy, perceive their goals as more relevant and rehabilitation more effective despite the functional gains between the groups remaining similar.

## Staff perspectives

- 15 staff members, 5 professions, 2 focus groups
- Five themes
  - Goal setting tools
  - Barriers
  - Keyworker role
  - Patient characteristics
  - Nature of goals



## Goal setting tools – folder, and keyworker interview

- *‘if someone has a got a real issue, it could take the whole week for something to come out and that’s a week gone by. At least with those questions things do come out earlier’*
- *‘the pack worked well if you spent time beforehand going through it with them’*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting

## Staff focus groups: Key worker role

- *‘... it is sometimes difficult in terms of who was key working with rotations and shifts for the nursing staff, if they were not there, helping patients who had got goal setting, erm, and someone else, in the old way would be able to step in and do that, I think, that was something that surprised me about how key their (ie keyworker’s) role needed to be’ (I1, 177-81).*
- *‘It’s actually quite a skilled job (ie being a keyworker) and difficult sometimes working through all those areas because it’s very much from the patient’s perspective*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting
- The key worker role is critical

## Barriers to goal setting

- *‘What you can offer people has to be realistic, so explaining what we can offer is important at the beginning. The collaborative (ie increased participation) style does help with that as you have more time allocated for discussion and evaluation within them’*
- *‘the old fashioned order, the conventional ways were less time consuming’*
- *but it was difficult to say to people (ie patients) who’ve had forty minutes or an hour with me today “So you’re not going to get in a therapy session”. It’s to do with the amount of staff at the moment and the time constraints we have to work with’*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting
- The key worker role is critical
- Effective goal setting is time consuming



## Patient characteristics

- *‘I sometimes think that the conventional way helps some people because they come in at say the onset of the illness and they wouldn’t know what they wanted to work on and they would say ‘Well, you tell me’*
- *‘It was so hard to drag information out of someone who has never been inclined to set a goal in their life’*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting
- The key worker role is critical
- Effective goal setting is time consuming
- Sometimes you need to set ‘activity’ rather than ‘participation’ goals *but* all patients want to be back to normal, so establish what normal was

## Nature of goals

- *‘because sometimes when they (the patients) have been more involved in goal setting they are more motivated*
- *‘As therapists we get stuck in our ways but the patients create interesting individual goals’*
  - *To roll my own cigarettes*
  - *To paint my toe nails*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting
- The key worker role is critical
- Effective goal setting is time consuming
- Sometimes you need to set ‘activity’ rather than ‘participation’ goals *but* all patients want to be back to normal, so establish what normal was
- Patients set goals meaningful to them but they can still be functional

## Staff focus groups: Staff experience

- *‘A lot rests with the experience of the staff, trying to predict outcomes whilst monitoring the course of a disease and trying to keep the patient’s intrinsic hopes and beliefs in the frame’*
- *‘With (the) conventional (mode of goal setting), sometimes it gained more of an opportunity for the team to discuss things about complex patients. ...It is sometimes more difficult when the patient is there, because you’re thinking about the cognitive and the physical issues, and trying to get all those in there. Sometimes when you are bouncing ideas off each other, you think “That might work!”, “Is that a reasonable goal?”, when you’re trying to set the goals with them, which is quite difficult when you’ve not been used to doing it’*

## Take home messages

- Early dialogue and preparation is needed for effective goal setting
- The key worker role is critical
- Effective goal setting is time consuming
- Sometimes you need to set ‘activity’ rather than ‘participation’ goals *but* all patients want to be back to normal, so establish what normal was
- Patients set goals meaningful to them but they can still be functional
- Staff enjoy good goal setting



## Goal setting - one aspect of patient centred care

- Patient involvement enhances autonomy and participation
- May improve task performance on simple tasks
- Successful goal setting underpinned by structures & processes that support patient centred care facilitates communication from patient to professional & professional to patient of
  - knowledge, (diagnosis, prognosis)
  - abilities/skills (patients current performance, therapists potential influence over performance, impact of cognitive impairment)
  - attitudes (family/individual values, impact of different styles of goal setting on staff-patient relationship)
  - resources (social services, informal networks,)

# Consensus

- Goal setting is a core component of the rehabilitation process,
- Goals should be specific, ambitious, relevant and time limited,
- Goals should have incremental steps that lead to progressive achievement.
- Goal setting has a major impact on the relationship between patient and professional, with the availability of professional time and expertise being key to the success of the process.

# Conclusions

- Goal setting is primarily a means of communication between individual and a team
- It needs to be supported by
  - structures (goal setting booklet)
  - processes (dedicated time)
  - resources (clinical and clerical)

## Patient decision aids

- make explicit the decision being considered. ✓
- contain a description of the condition, x
- the treatment options including a 'do nothing' option x
- the risk of side effects with each treatment option x
- the likely prognosis with different forms of treatment including the 'do nothing' option x
- how strong the evidence is for different options x
- a means of helping people clarify and communicate the values that inform their preferences. ✓
- can be used by patients before and during the meeting with the clinician to support them in their discussions. ✓
- aim is an active, informed and engaged patient.□□ ✓

## Challenge

- Time to build on our strong foundations for patient centred care and work to develop structures that support goal setting with patients as an aspect of patient centred and shared decision making. This means
  - Training staff in the necessary skills
  - Having structures/processes that facilitate dialogue as decision making aids facilitate dialogue between physician and patient
  - Allocating time to sharing information, communicating risk, supporting deliberation
  - Ensuring patients have copies of their goals