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The Service User and Carer Working Group's Journey Through the ALPS Programme

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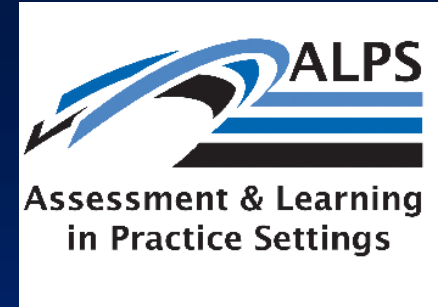
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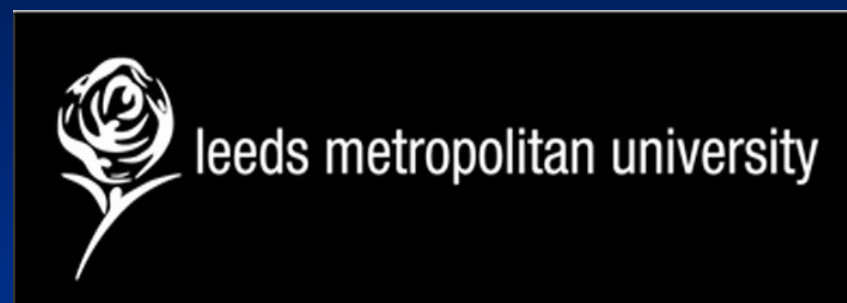
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# The Service User and Carer Working Groups journey through the ALPS Programme



# Caroline Plews, Christine Rhodes, Sue Sherwin & Jools Symons



# Long and winding road

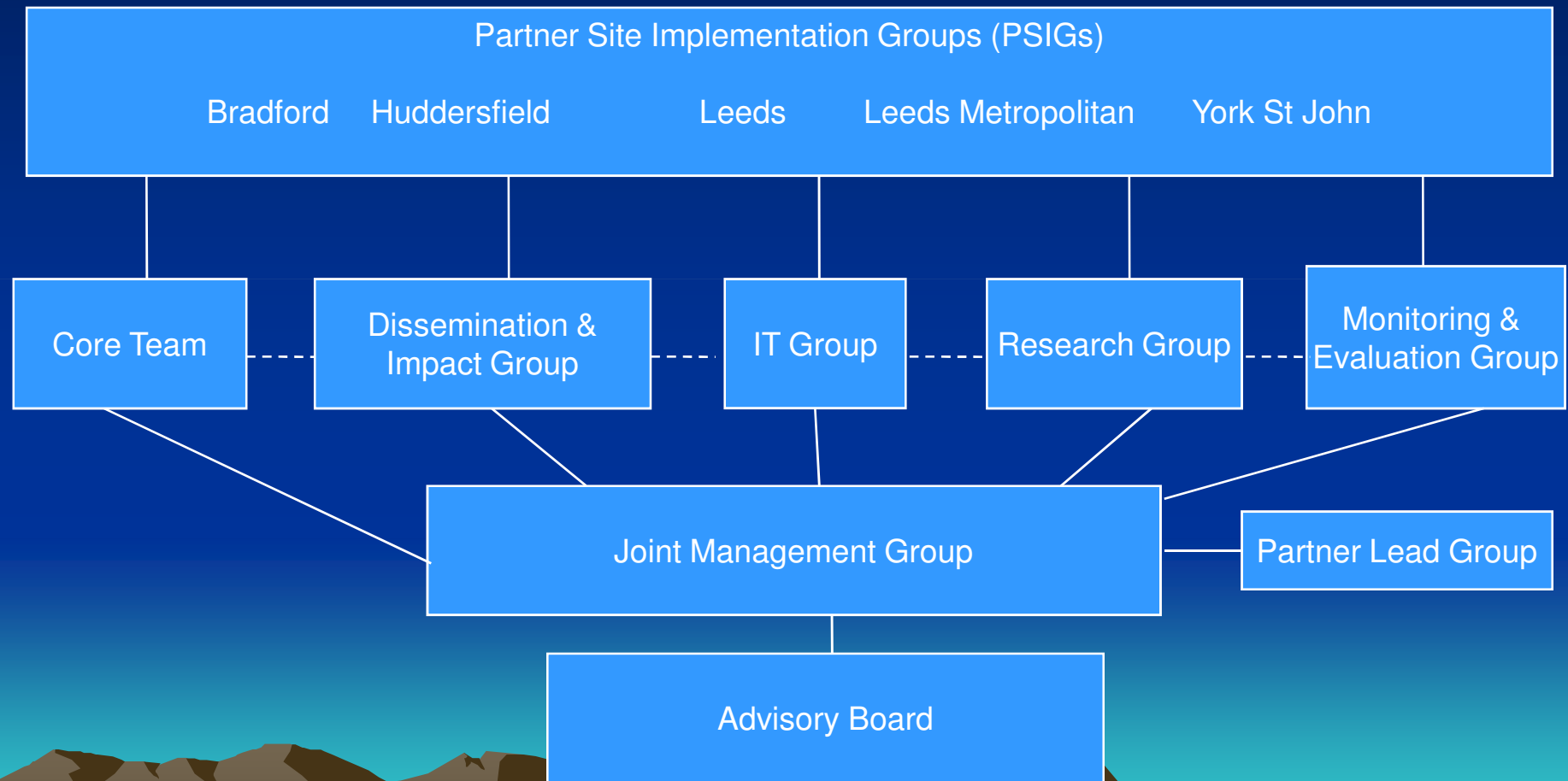


# Strategic Aims

- to develop and improve assessment and thereby learning in practice settings for all Health & Social Care students
- to develop the competence of people who support and assess Health and Social Care students in practice settings
- **to enhance the role of service-users and carers in assessment and learning in practice settings**
- to develop effective project management, evaluation and partnership working
- to research and disseminate assessment practice
- to respond to and influence national and international policy and culture in assessment



# How ALPS works



# In the beginning

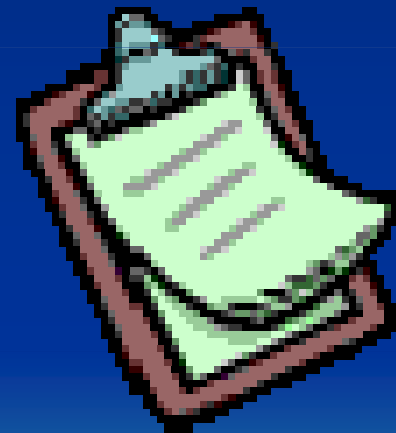


# Lines of Communication



# Drawing Board

- Terms of reference
- Two way communication
- Operational plan
- Work streams
- SU&C representation

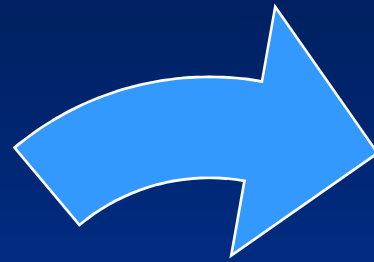


# Remuneration

- Different payments at each institution



# Flow of information



SU&C



# ALPS Good Practice Guidelines

<http://www.alps-cetl.ac.uk/essen/player.html>



# Collaboration between the partners

- What were our goals?
- Context of development
- Different levels of involvement between the Universities
- Examples of collaboration



# SHARED GOALS

- INVOLVEMENT OF SERVICE USERS AND CARERS IN ASSESSEMENT OF PRACTICE
- DEVELOP COLLABORATIVE RELATIONSHIPS WITH SERVICE USERS AND CARERS
- DEVELOP FRAMEWORKS THAT SUPPORT *BEST PRACTICE* FOR INVOLVEMENT
- DEVELOP INVOLVEMENT OF SERVICE USERS AND CARERS IN *ALL* ASPECTS OF EDUCATIONAL DELIVERY
- CHAMPION CULTURAL CHANGE AT AN INSTITUTIONAL AND INDIVIDUAL LEVEL



# THE GARDEN OF INVOLVEMENT ..... NOW



# THE GARDEN OF INVOLVEMENT ..... THEN



# DIFFERENT STAGES ON THE LADDER OF SERVICE USER AND CARER INVOLVEMENT

FULL INVOLVEMENT

PARTNERSHIP

CONSULTATION

TOKENISM

NO PARTICIPATION



# DEVELOPING FRAMEWORKS FOR SUSTAINABILITY



# DEVELOPING FRAMEWORKS

- Development of service user and carer role : job descriptions, possible models, development plans.
- How to develop networks with local people and communities.
- Legitimising the role: pay policy, service user and carer strategy.
- Sharing ideas: research, audit, data base innovative practice



# DEVELOPMENT OF INVOLVEMENT OF SERVICE USERS AND CARERS

- Across all Universities :
- Increase in the number of service users and carers involved
- Increase in the *types* of activity in which they are involved
- Individual and organisational change in culture



# Where are we now?



FULL INVOLVEMENT

PARTNERSHIP

CONSULTATION

TOKENISM

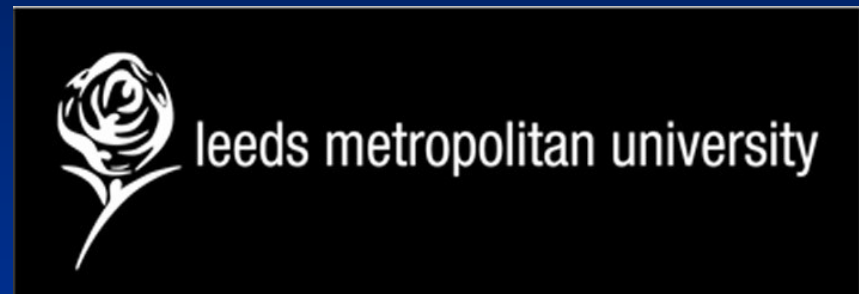
NO PARTICIPATION

# Competing drivers for the future

- Service user and carer agenda continues.
- Decreased resources in Universities.
- Future collaboration will require new goals to continue developing different types and levels of involvement.



# “What Matters to US”



# What Matters to US (Users of Services) in Shared Care and Decision Making



# Rationale and Context

- Health policy requires future professionals to support patients and carers in self-care, including decision making
- Working effectively in partnership needs appreciation of what patients and carers can do/offer and ability to respond flexibly
- History of collaboration of these four West Yorkshire Universities in establishing Patient Learning Journeys and support for effective working with patients and carers, modelling this for learners



# Rationale and Context

- ‘Back to basics’ urge of those who had been working with users and carers and were thus thinking more outside their professional silos
- The CETL ALPs (Assessment of Learning in Practice Settings) call for research proposals to inform their competency framework and assessment methods



# Research Aim

- To establish the essential skills and attributes that health & social care practitioners require to enable service user participation in decision making about their care.
- Funded by Assessment & learning in Practice Settings (ALPS) programme – Centre for Excellence in Teaching & Learning (CETL) project.



# Aims and Methods

- To establish a collaborative inquiry process with users and carers to explore what professionals need to do to help patients and carers play *their* part in shared care and decision making.
- To conduct a Delphi-type exercise to widen the inquiry to other users and carers, practitioners, students and academic teachers.
- To establish implications for the assessment of students in the practice setting and practice related learning in the academic setting.
- To build on these processes to co-design and test one or more assessment methods.



# Action Learning Groups

- Users and carers (US group) met 3 times in 3 groups and then all together, reflecting on experience
- Groups led by user and carer (university- employed) involvement workers
- All participants had been through Patient Learning Journey programmes
- Meetings were recorded, reflected upon and analysed in iterative process



# Emergent Findings

- ➡ **Time:** 'too much pressure on staff, they are not allowed to care due to time restrictions-high stress levels-this eventually makes them bail out
- ➡ **Respect and Person-centred:** 'The Nurse listened and understood where I was coming from. She looked at things from my point of view-I needed someone to listen to me and hear what I was saying to find a solution-she really wanted to help'.
- ➡ **Communication:** 'Speak at our level but don't assume our level. I really want to know you're listening'



# Emergent findings continued...

- ➡ **Power:** 'As his carer I know more things about him than they do'. 'Both Dr and Patient are experts so should work together'
- ➡ **Team working:** 'communicating with other professionals to smooth our way to getting help'
- ➡ **The Organisation:** 'OT very young and very open minded-not worried about ticking boxes and pleasing management- no doubt this will have to change'
- ➡ **The relationship:** 'The Consultant was very apologetic- he admitted that 'Mother knows best'-so I have great respect for him'. 'I came out lighter because he'd listened to me and he'd lightened the load'



# Learning and process outcomes

- Learning how to lead from a user perspective: university workers had to lead at the start as it was university based and our agenda, but we led from our own personal experience, not from our professional title
- Learned to encourage dialogue so the group grew their ideas: 'I learned how to listen, really listen, again'.
- Effect on those involved (i.e. usual health, wellbeing and employment outcomes) enhanced by contributing more fully from the beginning: what is important to assess?
- Users and carers can add vital depth and breadth to understandings from professional silos if given resources



# Learning and process outcomes

- Still struggling with contradictions of different research paradigms! Still working on....
- Action Learning groups with service users /carers, tape recorded and transcribed.
- Thematic analysis – statements related to shared care and decision making formed basis for a survey.
- Survey statements taken back to Action Learning groups for approval.



# Survey

- Survey sent out to 3 stakeholders –

Service Users/ Carers – wide range of experiences.

Students – across 16 professions

Academics – across 16 professions

- Statements ranked or rated option to add comments
- Colour coded to enable attribution of response to stakeholder group.



# Sample Question

Do you feel that how a person dresses makes a difference to their treatment by professionals?

Yes ☐

No ☐

If you answered 'yes' please could you explain this a little below:

Please tick one of the boxes opposite.



# Sample Question

Please rank the following attributes of professionals from the most to the least important to you, where 1 is the most important and 6 is the least important:

Being honest ☐

Being flexible ☐

Being up-to-date ☐

Avoiding jargon ☐

Being down to earth ☐

Listening ☐



# Broad Outcomes of resulting modified Delphi

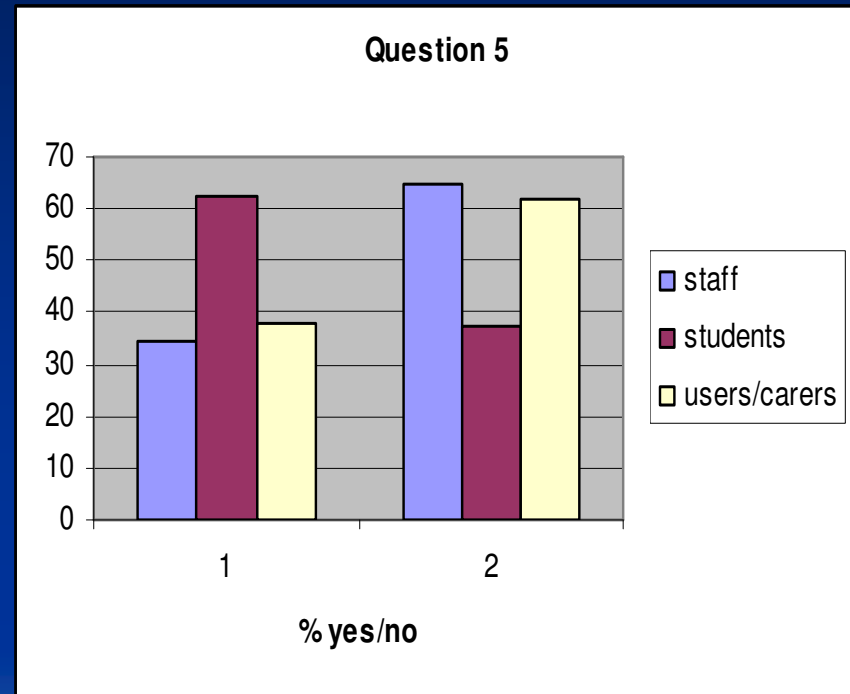
- Satisfactory return rate
- No major surprises in the analysis to date
- Data confirms previous work by US ALG groups:
- It is not just knowledge, skills and attributes that are important
- Many extraneous factors affect interactions.



# Some Findings

## QUESTION 5

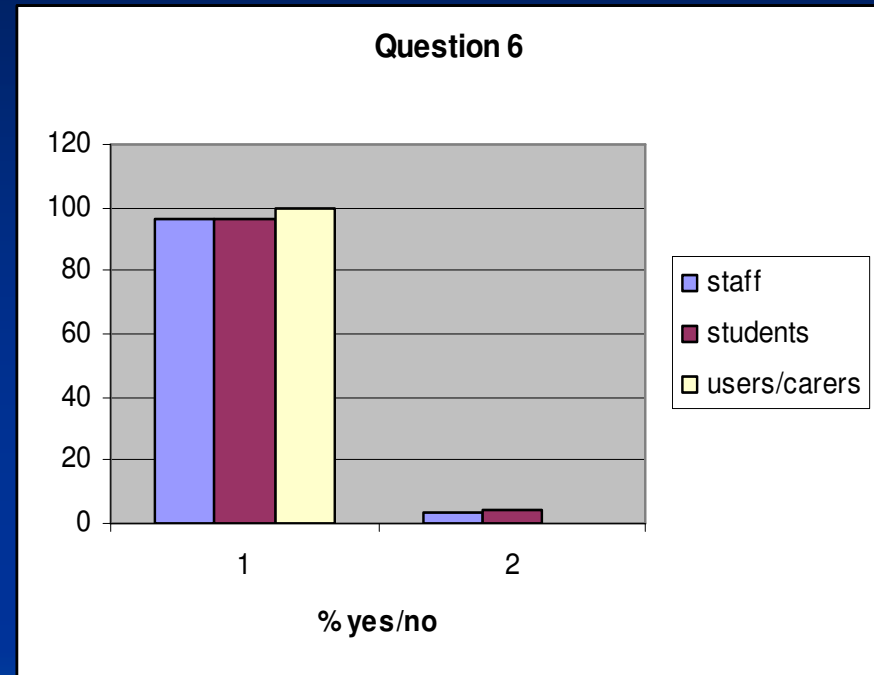
It is important for professionals to behave in a way that marks them out as different from patients/service users and carers:



# Some Findings

## QUESTION 6

**Professionals should check if a person can or cannot understand what is being discussed:**



# Outcomes

- Different perspectives – handwashing – much more than hygiene function – issue of respect.
- Dressing up for an interaction with the Doctor
- Rituals



# Limitations

- Researcher influence – interaction with service users/carers
- Validity - Transferring dialogue into statements for survey. Eroded validity
- Ambiguous statements open to different interpretation.
- Uniqueness interaction – not transferable.



# Value

- Service user led/ focused research.
- Richness in the dialogue - Audio clips effective way of demonstrating patient/ user opinion.
- Collaborative work- strength in numbers.
- Use of self – iterative reflective methodology.
- Intuition - facilitators were embedded in service user interactions

# Next steps

- Dissemination
- Write up
- Reusable learning objects – pod casts.
- Value of talking to one another.
- Continue collaborative working.



# Acknowledgements and contacts

- Project funded by ALPS CETL
  - [www.alps-cetl.ac.uk](http://www.alps-cetl.ac.uk)
- Project Steering group:
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  - Chris Essen, Sam Samociuk, Leeds University School of Healthcare
  - Mike Bush, Sue Sherwin, Leeds Metropolitan University
  - Caroline Plews, Jane Priestley, University of Bradford
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# Conclusion : Overall Successes of SUCWG

- Collaboration
- Community of Practice
- Cultural Shift

