



**Assessment & Learning
in Practice Settings**

**ALPS Research Capacity Final Report
(2 of 3)**

**What Matters to US
(Users of Services)?**

*Discovering and applying user and carer perceptions of
the requisite skills and attributes of health and care
students to enable shared care and decision making*

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In 2007 ALPS awarded funding to three projects which were designed to advance the goals of the ALPS programme and build additional research capacity within the partnership, to further the cross-institutional goals of ALPS

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The project team worked in two project groups, focussing on two different methodologies (group action research and Delphi inquiry) and meeting regularly as a whole project team. Penny Morris, Jools Symons and Chris Essen led the first part of the investigation with the **US** groups; Sue Sherwin the second part, the development of the Delphi survey and analysis; Jane Priestley led the qualitative analysis of the survey and related podcasts. Dissemination is led by Christine Rhodes.

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Summary

Short project summary

Professionals need to learn how to support patients and their carers play a greater part in care and decision making. Teachers across four universities have been collaborating with service users to develop their role in professional learning, during a Patient Learning Journey programme which enables users to learn from their experience and help others to learn from theirs. The work led to this enquiry into the attributes, behaviours and context that medical, health and social care students require for effective partnership working, and how to assess these.

Patients/carers met in groups (which were facilitated by university user involvement workers and recorded) during an iterative action research process, to examine and apply their experience to student assessment. Continued reflection was undertaken with support from an observer/reflector academic and the project team, drawn from the four universities involved. A modified Delphi study was then undertaken with more users, plus multi-professional students and clinical teachers.

Investigating competences from this perspective has revealed important differences from research undertaken in professional silos. This study supports holistic framing of teaching and assessment, incorporating notions of ethics, communication and team working into person-based practices. Without public engagement, there is a missing expertise in curriculum development, as in healthcare.

Full project summary

The aim of this project was to deepen and build on understanding of service user and carer perceptions of the attributes, behaviours and context that health and social care students require for effective partnership working with users and carers. It offers another perspective on professional competences, with the idea that professionals need to learn how to support patients and their carers to play a greater part in care and decision making - an imperative for transforming relationships in health care, arising from evidence and policies for how to deal with long term conditions.

Service users and carers (the **US** group) were involved in a collaborative inquiry process with practitioners, students and academic teachers. The **US** group had all been participants in the Patient Learning Journeys programme, where patients, mainly with long term conditions, and carers reflect together in small groups on their experiences of illness and care, sharing their experiences and their learning. They then focus on how to offer these for student and professional learning. The programme was developed first in the School of Medicine at the University of Leeds and taken forward in collaboration with the University of Leeds, School of Healthcare, and the universities of Bradford, Huddersfield, and Leeds Metropolitan. The project was funded by the West Yorkshire Strategic Health Authority, then by the NHS Yorkshire and the Humber. The steering group for that project collaborated further on this study.

The **US** group met in small groups and then came together, during an iterative action research process, to examine and apply their experience to student assessment. These groups were facilitated by two university user and carer involvement workers and recorded. Notes of the meetings were fed back to participants for further discussion. In between meetings, the involvement workers reflected on the process and emergent findings, with support from meetings with an observer/reflector academic and the project team. The investigation continued during a modified Delphi study with a wider group of users and carers, as well as

students, practitioners and teachers. This stage of the study included comparison of user perceptions with those of students and academic teachers.

Patient and carer participation brought fresh voices to the discussion of professional competences in the ALPS project. Starting from their own perspective of their needs from professionals, the outcomes of this investigation with users support a holistic framing of teaching and assessment, incorporating notions of ethics, communication and team working. The users' talk focussed on notions of openness, flexibility, not making assumptions, sharing ownership and thus being able to find solutions together, as well as the context students will need to enable them to demonstrate these capacities. Involving 'expert' patient and carer learners also brought to the inquiry their understanding of effective learning for transformational change. They are aware of the difficulties inherent in assessment: *"the more we say 'this is what you have to do and say' the more it becomes a tick box exercise for them"* (**US** group participant).

The **US** group developed further their confidence and capacity to contribute to education at a more significant level than mere consultation. The academics involved also learned more about the value of working in a truer partnership with users and carers, and this knowledge was taken into the core ALPS service user and carer working group, as well as building capacity in individual universities. Outcomes from work with users in this study include the development of assessment tools to complement the current ALPS tools; work groups of users and carers who are co-piloting these tools; co-teaching from patient and carer perspectives across the universities and professions; co-development of nursing and medical examinations within one university; co-production of clinical assessment resources; participation in curriculum review and co-creation of digital and reusable learning materials, as well as presentations at local, national and international meetings and publications in preparation.

Background

During the last decade government initiatives to modernise health and social services have driven a cultural change aimed at delivering a genuinely patient-centred approach to care (DOH 2000). There has been widespread acknowledgement of the need to involve patients and the public in all aspects of health care (DOH 2005) and current policy sets out the statutory requirements in the Health & Social Care Act, 2001. The Department of Health produced a draft framework for creating a stronger local voice in the development of health and social care services (DOH 2006), some regions developed principles for service user involvement in educational practice (Trent NHS 2005) and work got underway (DoH 2005ii, DoH 2007).

The challenge has been to translate these policies into practice, not just in service delivery but also in education; ensuring that the principles for user involvement are adhered to at all levels of health care. Involving service users in the education of professionals can influence practice by sharing experiences with the practitioners of the future, considering the needs and views of patients as central to management from the earliest stages of a professional's career.

This change culture is affording new opportunities for service users and carers to influence practice through involvement in the education of health and social care professionals. Practice placements provide an ideal setting for service users and carers to be actively involved in the learning experience of the student, including participating in the assessment of 'fitness to practice'. User and carer involvement should be supported by a systematic process that includes involvement from the initial stages, from the identification of common competences for practice, to formulation of an assessment tool and ultimately participation in the assessment process. User voices have already defined the standards expected for appropriate involvement (Gell and Anderson 2005); this study has supported leading efforts in the region and nationally to apply learning from involvement in educational change (ALPS 2009, PEPIN network <http://pepin-uk.net/>).

The study grew out of an existing collaboration between the four universities involved, supported first by the West Yorkshire Strategic Health Authority and then by the NHS Yorkshire and the Humber, building on a widening participation initiative at the University of Leeds, School of Medicine that supports individuals with long-term conditions and carers to become involved in the delivery of health professional education. A 'Patient Learning Journey' programme was established across West Yorkshire and then beyond, from which the **US** group emerged.

Our learning from this collaboration enabled us to identify what helps a meaningful, as opposed to token, contribution by the public. The key is recognition of the value of the capacities of users and carers (rather than an emphasis on their deficits and needs) and of their role as co-producers in health, and then applying that in processes that support the necessary transformation of relationships in health and social care (Thistlethwaite and Morris 2006, chapter 7, Morris et al 2007, Morris et al 2009).

This study also built on local work that has contributed to international understanding of the growing field of public involvement in professional learning (Towle et al 2006; www.leeds.ac.uk/medicine/meu/voices06.index.html). In particular, the project employed methods of involving users and carers in developing re-usable learning materials in e-learning approaches developed at the University of Bradford (Priestley et al 2006, Priestley and Hellowell 2007).

Working extensively with users and carers both across universities and in our own departments led us to think more outside our professional silos and we had a 'back to basics' urge to involve the **US** group in re-thinking professional/user interactions. We were advocates

for user contribution to all aspects of curricula and aware of its possibilities and barriers to these. We decided to investigate how patient-centredness (*'demonstrated to be a paramount feature of high-quality care.....Students need to develop a commitment to partnership'* (Fragstein et al 2008)) could best be achieved by looking at how users and carers can be helped to fully play *their* part in care. To do this effectively, users and carers needed to be supported to become our educational and research partners (Hasman et al 2006).

Aims and objectives

The aims of this project were to build on and deepen important learning about the capacities of service users and carers to take a fuller part in care, to understand more about how this can be enhanced by professionals and in student learning and to support the ongoing development of users and carers' contribution to professional learning. Our objectives were:

- To establish a collaborative inquiry process with the **US** group to explore user and carer understanding and perceptions of the behaviours, attributes and context that health and social care students require for effective communication, shared decision making and partnership working with users and carers
- To conduct a modified Delphi exercise to widen the inquiry with more users and carers from the Patient Learning Journeys programmes
- To extend the inquiry with 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
- To inform the design of assessment tools for the core common competences of the ALPS project
- To provide a reference group for validation and co-creation of assessment methods for current and developing teaching (e.g. OSCE stations, scenarios for simulated patients, reflective portfolios)

Methodology

To build the capacity of users to contribute to the study, we needed to mirror our focus on how professionals can enable user contribution to care and decision making. We chose research processes that are reflexive and participatory and in which we had some experience (Alvesson and Sköldbberg 2000, Bradbury et al, in preparation), that allow for exploration of the complexities of roles and relationships in modern healthcare (Steinberg 2005) and attempt to model the transformation of relationships needed (Chiu 2003). We decided to work first with users and carers in an action research mode with collaborative, rather than conventional, focus groups and to distil their findings into a survey inquiry.

We then needed a way to widen the inquiry to explore and compare student, academic and practitioner perceptions. The Delphi survey technique is a research method originally designed for forecasting and has been used by policy makers since the 1950's (Rowe and Wright, 1999). It has been used to determine service user preferences (Walker 1994; Lowe et al 1995). It is a consensus method which can enhance decision making in health and social care by transforming opinion into group consensus (Hasson, Keeney and McKenna, 2000). This is carried out through an iterative, multistage process that refines opinion data. Opinions are initially drawn from a group of experts; in this study the experts are the service users and carers. These are then developed into a survey of further informed people – in this case, other service users and carers who had undergone the Patient Learning Journey programme (the **US** group), medical, health and social care students and educators. Two members of the project team had previously conducted Delphi inquiries.

Method

Part 1: A collaborative group inquiry

A diverse group of users and carers who had been through the 'Patient Learning Journey' programme were recruited. The programme involves users and carers sharing their experiences in health and social care, evaluating what could have been done by the professionals, and also by themselves, to improve relationships and outcomes, and, finally, considering how to help learners gain from their experience. They now met as the **US** group in three separate groups of 5 or 6 to further examine their experiences of involvement in decisions and partnership working in the practice setting and to consider how students and professionals can enable them to play *their* part in shared care and decision making. The sessions were facilitated by two university user and carer involvement workers, one of whom was the lead facilitator for the Patient Learning Journey programme. After each session, these facilitators reflected on the meetings, aided by sound recordings, and met to review their notes of the meeting, before meeting with the next **US** group, in an iterative process.

They were supervised and supported in this by an academic communication specialist who encouraged them to interrogate the data in the light of their own experience and reactions as service users and as facilitators, as well as offering further theoretical perspectives. This academic also observed the first meeting of the **US** group. The meetings with the **US** groups were refined as a result of these reflections. The cumulative reflections were circulated to the project team for email comment and revisited in project team meetings. **US** group members also received the notes of their meetings for further reflection and comment.

The meeting of the whole **US** group was presented with an initial framework (developed during the reflective meetings) for considering their discussions and the way forward (Appendix 1). The academic specialist for this stage also attended this meeting, along with the lead for Stage 2. During a series of small and larger group discussions, the **US** group prioritised what

they identified as important criteria for assessing students' capacity to support them in shared care and decision making (Appendix 2).

We obtained permission from the **US** groups to edit excerpts from the sound recordings of their discussions for learning materials and involved them in this.

Part 2: A modified Delphi inquiry

The service user and carer group workshops raised a number of important issues in relation to what matters to service users and carers when accessing and using health and social care services. In order to try and establish if these views were held more broadly, a Delphi survey was conducted, with questionnaires going out to three groups: the wider group of service users and carers; students of health and social care programmes in Higher Education Institutions (HEIs); and staff who teach on health and social care programmes in HEIs. A consensus of opinion was sought about the behaviour and communication strategies that support user and carer active engagement in the decision making process in care.

The data from notes and recording of the whole **US** group meeting was gathered for the project team by the leads for project parts 1 and 2 and discussed. A list of key issues was taken back to the **US** group for further refinement to inform the content of the Delphi questionnaire. The first draft of the questionnaire was again reviewed by the **US** group and this was amended, with the project team, in accordance with their feedback.

The number of stages taken in a Delphi survey is arbitrary but generally the more iteration, the more robust the consensus. Turoff and Linstone (1979) warn of the pitfalls of either over- or under- refining the original data, both of which can reduce the original intention of the 'experts'. In this study the amount of iteration seemed appropriate in both achieving consensus on the questionnaire content and in staying true to the original opinions expressed.

In using a Delphi survey to confirm the expert opinion, rather than to forecast an event or trend, this study has veered away from the true purpose of the Delphi approach and as such a modified Delphi has been used.

The questionnaires were administered in person to students and staff across the four universities and by post to the further group of users and carers. The analysis of the questionnaires, including free comments, was conducted by the part 2 and qualitative leads and discussed in the project team. It was also discussed at a meeting with members of the **US** group with the project team, where the project was reviewed.

This continued attention to rigorous, iterative involvement of users and carers, as well as the academic team, was important for effective and ethical action research.

Implementation

A project team was established, with largely the same membership as the earlier project on developing Patient Learning Journeys from which this ALPS study grew. This continued hard-won collaborative practices and good relationships across the four universities. It also meant that the group memory of how to achieve real, not token, co-working informed and deepened the participative research with users and carers. It is important to note that three members of the eight-strong project group were designated user/carer workers and all members were comfortable to bring their patient/carer/user selves to the table, thus ensuring a consistent user voice throughout the research process. Research leadership across the two methodologies and effective project management were enhanced by the longstanding nature of this group.

The lead facilitator for the Patient Learning Journey programme set up and led the series of group workshops with users and carers, recruited from the programme. She was supported by the other University of Leeds involvement worker, ensuring a reflective user partnership for the project. Their process was supported by an academic specialist and the project team, as described above.

Already, the **US** group members were active in the universities involved. When there was severe time slippage during ethical approval seeking, our objective to involve students was addressed through individual site work. This was thus informed by, but not fully working with, data from this research. This means that the project materials, co-produced with users/carers/students, are being piloted in single institutions so far. We intend to share these across our universities in time and future dissemination events will support this.

Results

The initial framework for bringing together the work of the different **US** workshops was drawn up during the reflective meetings with the user leads and their academic support. This had four categories: Attention; Environment, Knowledge Diversity and Attitude (see Appendix A).

This was used during the large workshop that brought together the three **US** groups to share and re-examine their findings from their group work. These findings were presented under abstract headings and quotes from the groups were used to bring these to life, e.g. 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.”*; Knowledge and Power: *“As his carer I know more things about him than they do”. “Both doctor and patient are experts and should work together”* (see Appendix B).

This information was drawn up into a list of key issues for iterative re-visiting by the project team and **US** group and the stages outlined above in the Method section developed a modified Delphi questionnaire (Appendix C).

Analysis of the survey data indicates that there is general agreement on what is most important for service users and carers when using health and social care services across all three survey groups, students, staff and users (See Appendix D). However, in relation to question 5: *“It is important for professionals to behave in a way that marks them out as different from patients/service users and carers”* the student survey group were 50% more likely than the staff or service user/carers to answer ‘yes’.

Whilst this Delphi confirmed that the views of the original workshops groups were more widely held, what became apparent from free text annotations on the questionnaires and from discussions was that the rich meaning of the original **US** group discussions became ‘lost’, once it was reduced to a single question and removed from the original context. This has been considered to be one of the main disadvantages of using the Delphi approach: *“Just as a linear progression of words fails to communicate a Rembrandt painting, so a panellist may be unable to communicate his views or insights by means of a concise sentence or even by diagrams. We also observe that different cultural groups communicate in diverse ways; forcing them into a conventional Delphi format may destroy their message.”* (Turoff and Linstone (1979), pg 565).

Important learning from the project was that of the participants: both professionals and users report significant personal development and increased capacity for partnership.

Outputs

- Reflective tools for both service users/carers and students to enable guided reflection on encounters with patients and to facilitate active participation
- Work groups of users as part of pilot teams for these and the core ALPS tools
- Scenarios for assessment for clinical communication
- A more informed service user and carer perspective to supplement the professional perspectives of communication and other competences identified through the ALPS project so far
- A collaborative forum for educators, service users and students to design teaching and assessment
- Re-usable learning objects in the form of podcasts and film clips for learning and assessment
- A series of presentations at local, national and international level, including at the University of Huddersfield annual research day and the conferences of UK Council for

Outcomes

We established useful methods for involving users and carers as co-producers in assessment, as well as reference and work groups to support further development with user/carer perspectives. Service users and carers have been able to use a collaborative forum to influence and shape assessment practice and their capacities and confidence have been greatly enhanced.

We have produced re-useable learning objects to develop insight into the communication process from the service user and carer perspective, which will enhance the support of students prior to practice and in the practice setting

The learning of our project team of educational leaders has been effectively cascaded in the universities. User and carer perceptions contributed to a meaningful assessment experience for all concerned.

Dissemination by publication, conferences, formal and informal networks (including ones led by members of the project, e.g. the PEPIN network), emphasising ethical and effective involvement, is influencing education locally, nationally and internationally.

The participative aspects of the project helped us realise the fuller potential of the contribution of the users and carers. We are keen to extend and refine these participative processes. We also understand more about the 'use of self' and the validity and place of personal experience in research activity, discovered through our shared, reflective process.

Conclusions

Service users and carers are too often a missing expertise in the development of professional curricula. It is possible to involve them ethically and effectively, but this requires a similar reflective engagement by the professionals involved.

Implications

Given the potential of involving users and carers in professional learning, we need to build this into our curriculum development processes. Given also its value to all concerned, it is worth applying this principle seriously.

Recommendations

Opportunities for educators, practitioners and service users to learn together should be developed.

Service users should also have their own mantra to maintain their confidence in their own experience.

Effective individual and group reflective processes need to be in place for effective learning with users and carers.

References

ALPS 2009 <http://www.alps-cetl.ac.uk/ServiceUsersCarers.html>

Alvesson, M. & Sköldbberg, K. (2000). *Reflexive methodology. New vistas for qualitative research*. Sage, London.

Andersson E, Tritter J, Wilson R (2007). *Health democracy: the future of involvement in health and social care*. INVOLVE/NHS Centre for Involvement, Warwick.

Bradbury H, Kilminster S, McGoverin A, Morris P, Quinton N, Zukas M. (in preparation). *Recognising living with long-term health conditions as learning journeys: a life history perspective*.

Chiu, L (2003). Transformational potential of focus group practice in participatory action research. *Action Research*, 1 (2): 165-183.

Department of Health (2000) *The National Plan for the NHS . A Plan for Investment, a Plan for Reform*, DoH, London.

Department of Health (2005) *Commissioning a patient -led NHS*. DoH, London.

Department of Health (2005ii) *'Now I feel tall': What a patient-led NHS feels like*. DoH, London.

Department of Health (2006). *A Stronger Local Voice: A framework for creating a stronger local voice in the development of health and social care services*. DoH, London.

Department of Health (2007). *Health Committee's Report on Patient and Public Involvement in the NHS*. DoH, London.

Fragstein M, Silverman J, Cushing A, Quilligan S, Salisbury H, Wiskin C (2008). UK consensus statement on the content of communication curricula in undergraduate medical education. *Medical Education*, 42: 1100-1107.

Gell C, Anderson J (2005). *Learning with Users: Good Practice Guidelines*. mhhe, Nottingham.

Hasman A, Coulter A, Askham J (2006). *Education for Partnership*. Picker Institute, Oxford.

Hasson F, Keeney S, and McKenna H (2000). Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing*, 32(4):1008-15.

Lowe JB et al (1995) *Community perceptions of bowel cancer: a survey of Queenslanders*. In Bowles N. (1999) *The Delphi Technique*. Nursing Standard. 13 (45) 32-35.

Morris P, Armitage A, Dalton E, Gaines M, Katz A, Lane R, O'Neill F, Reed J, Symons J (2007). *Moving from tokenism to co-production: implications of learning from patient and community voices in developing patient-centred professionalism*. Paper presented at conference Professional Lifelong Learning: Critical Debates about Professionalism. http://www.leeds.ac.uk/medicine/meu/lifelong07/papers/Penny_Morris.pdf

Morris P, Dalton E, McGoverin A, Symons J (2009). Preparing for Patient-Centred Practice: Developing the Patient Voice in Health Professional Learning. In: Bradbury H, Frost N, Kilminster S, Zukas M. *Beyond Reflective Practice*. Routledge, Oxford.

PEPIN network

[http://www.peopleandparticipation.net/display/Participationlibrary/Professional+Education+Public+Involvement+UK+Network+\(PEPIN\)](http://www.peopleandparticipation.net/display/Participationlibrary/Professional+Education+Public+Involvement+UK+Network+(PEPIN))

Priestley J, Hellowell M, Hinton J, Sharples R, Walkden B (2006). Promoting a patient centred approach in pre-practice education through the use of blended learning. In: *Blended Learning – Promoting Dialogue in Innovation and Practice*. University of Hertfordshire. Proceedings of the First Annual Blended Learning Conference. P.228.

Priestley J, Hellowell M (2007). *E-learning and Service User Involvement*. A symposium at the Festival of Learning, Health Sciences and Practice Subject Centre, Higher Education Academy.

Rowe and Wright (1999): The Delphi technique as a forecasting tool: issues and analysis. *International Journal of Forecasting*, Vol 15, 4, October 1999

Steinberg, D. (2005). *Complexity in Healthcare and the Language of the Consultation*, Radcliffe, Oxford

Thistlethwaite J, Morris P. *The Patient Doctor Consultation in Primary Care: Theory and Practice*. Royal College of General Practitioners, London

Towle A, Weston W. (2006). Patient voices in health professional education. *Patient Education and Counseling*, 63: 1–2

Trent NHS Strategic Health Authority. (2005) *Principles for Practice; Involving service users and carers in health care education and training*. Trent Multi-professional Deanery. Nottingham

Turoff M and Linstone H (1979). *The Delphi Method: Techniques and Applications*

Walker A (1994) A Delphi study of research priorities in the clinical practice of physiotherapy. *Physiotherapy*. 80(4):205-207

What Matters to US Appendix A:

Framework derived from reflection on US group work

ATTENTION:

- Attention to self
- Attention to the other
- Attention to the relationship
 - Aware/observant/empathy/flexible
- Visible respect (hygiene)

ENVIRONMENT:

- Managing the environment of the encounter
 - Setting the scene
 - Flexible
 - Time management
- Supporting the use of resources
 - Record
 - Team
 - Community
- Dealing with people within the context of their lives and communities

KNOWLEDGE DIVERSITY:

- Communications skills
- Clinically up to date
- Flexible

ATTITUDE:

- Open
- Non judgemental
- Self reflective
- Honest

What Matters to Us Appendix B:

Initial findings from US group work

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."*

Knowledge and Power: *"As his carer I know more things about him than they do". "Both doctor and patient are experts and should work together."*

Time: *"Too much pressure on staff, they are not allowed to care due to time restrictions – high stress levels eventually makes them bail out."*

Communication: *"Speak at our level but don't assume our level." "I really want to know you're listening."*

Team working: *"Communicate with other professional to smooth our way in getting help."*

The Organisation: *"OT was very young and open-minded – not worried about ticking boxes and just pleasing management – no doubt this will have to change."*

The Relationship: *"The consultant was very apologetic and he admitted that 'Your mother knows best' so I have great respect for him." "I came out lighter because he's listened to me and lightened the load."*

What Matters to US APPENDIX C:

Sharing care and decision making questionnaire

This questionnaire is to help us see if there is agreement on what is important in working together in shared care and decision making between professionals, patients/service users and carers. In this questionnaire the word 'professional' can be a nurse, doctor, physiotherapist, social worker or anyone who provides support and/or care for you through health and social care services.

<p>1. Do you feel that how a person dresses makes a difference to their treatment by professionals? Please tick one of the boxes opposite.</p> <p>If you answered 'yes' please could you explain this a little below:</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>
<p>2. 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:</p>	<p>Being honest _____</p> <p>Being flexible _____</p> <p>Being up-to-date _____</p> <p>Avoiding jargon _____</p> <p>Being down to earth _____</p> <p>Listening _____</p>
<p>Is there anything else that you feel is important? If so please write this here:</p>	
<p>3. For the following questions please indicate how far you agree or disagree with the statements by circling the answer that is closest to yours:</p>	
<p>3.1 Skilled professionals are able to make accurate assumptions about how common situations will affect a person:</p>	<p>Fully agree Partially agree Partially disagree Fully disagree</p>
<p>3.2 Different health and social care professions should work together to co-ordinate the activity around what is convenient for the patient/service user and carer:</p>	<p>Fully agree Partially agree Partially disagree Fully disagree</p>
<p>3.3 Getting the job done is more important than trying to explain everything to the patient/service user and carer:</p>	<p>Fully agree Partially agree Partially disagree Fully disagree</p>
<p>3.4 Rules get in the way of professionals being creative and taking therapeutic risks:</p>	<p>Fully agree Partially agree Partially disagree Fully disagree</p>

3.5	In practice professionals don't have time to focus on the patient/service user and carer as a person:	Fully Agree	Partially agree	Partially disagree	Fully disagree
3.3	It is acceptable for a professional to admit not knowing the answer to a problem as long as they have shown empathy and understanding:	Fully Agree	Partially agree	Partially disagree	Fully disagree
3.4	It is as important for patients/service users and carers to see handwashing being done as it is for it to be done properly:	Fully Agree	Partially agree	Partially disagree	Fully disagree
3.5	Professionals check out their assumptions with patients/service users and carers about their needs:	Fully Agree	Partially agree	Partially disagree	Fully disagree
3.6	Professionals recognise that a person's need for independent decision making may fluctuate:	Fully Agree	Partially agree	Partially disagree	Fully disagree
4.	This question relates to the relationship between professionals and patients/ service users and carers. Please rank the behaviours opposite where 1 is the most important and 5 is the least important: Is there anything else you'd like to tell us about relationships? If so please write this here:	Showing respect — Sharing power — Giving time — Being open and accepting — Being self-aware —			
5.	It is important for professionals to behave in a way that marks them out as different from patients/service users and carers	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
6.	Professionals should check if a person can or cannot understand what is being discussed?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
7.	Do you think personal health and social care records should be: (please tick one box only)	Kept by the patient/service user or carer? <input type="checkbox"/> Kept mainly for use by the professional? <input type="checkbox"/> Kept by the professional and always available for the patient/service user or carer to add comments? <input type="checkbox"/>			

Thank you for completing this questionnaire

What Matters to US: APPENDIX D

Delphi collated percentages for all three groups

All percentages calculated to the nearest 0.5%.

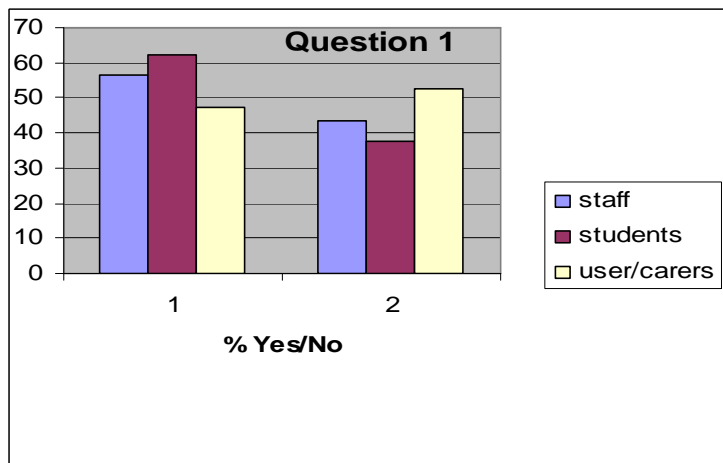
Staff n = 31; students n = 24; service users/carers n = 22

QUESTION 1

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

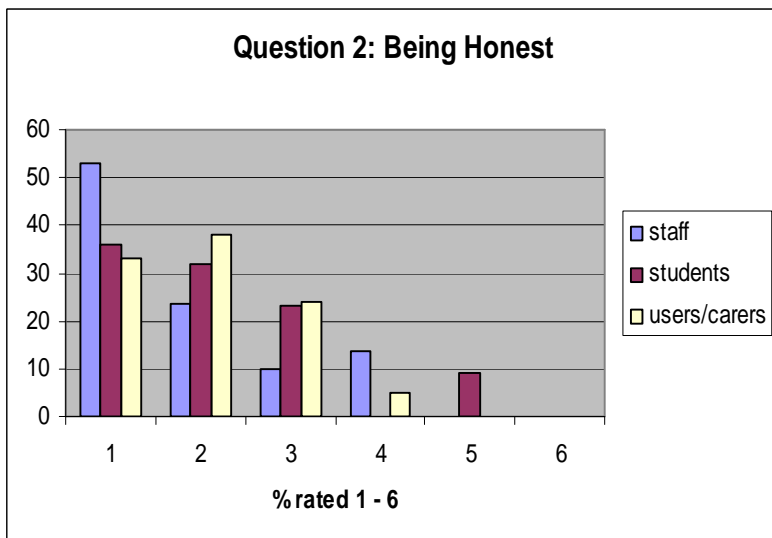
Please tick one of the boxes opposite:

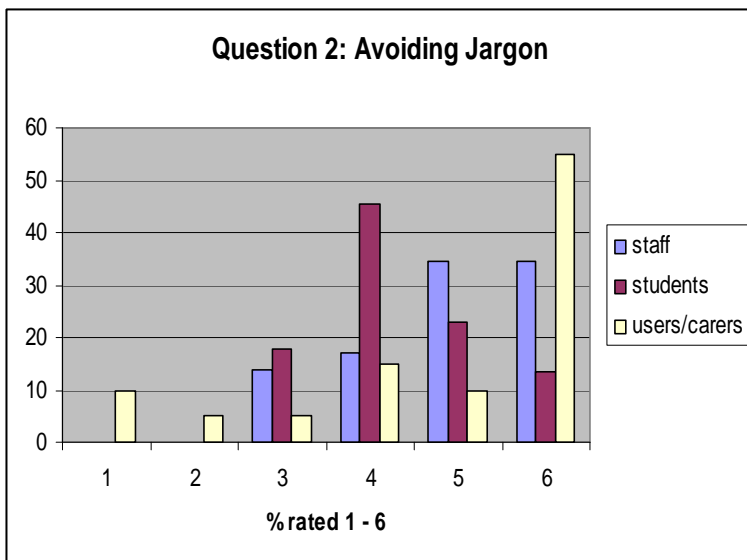
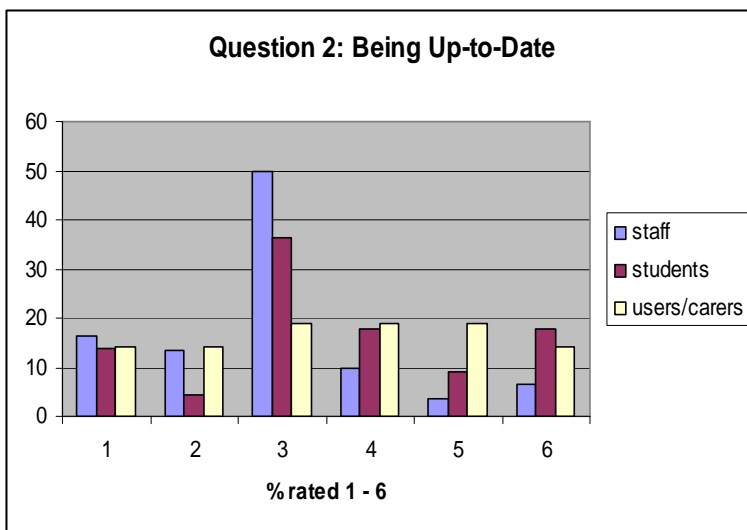
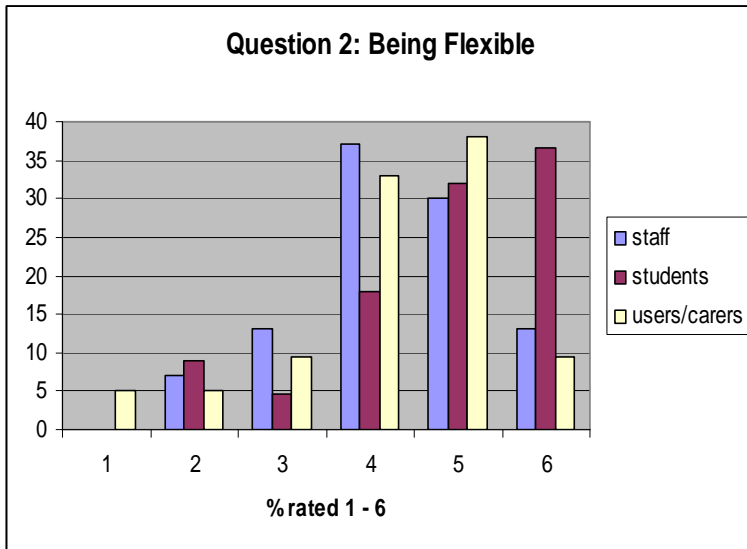
(1 = yes, 2 = no)



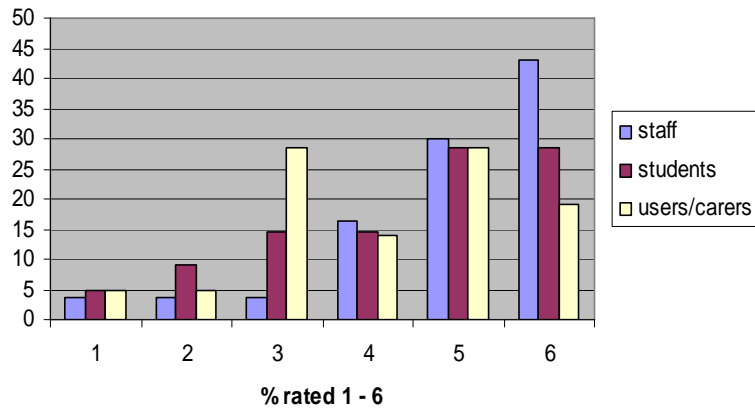
QUESTION 2

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:

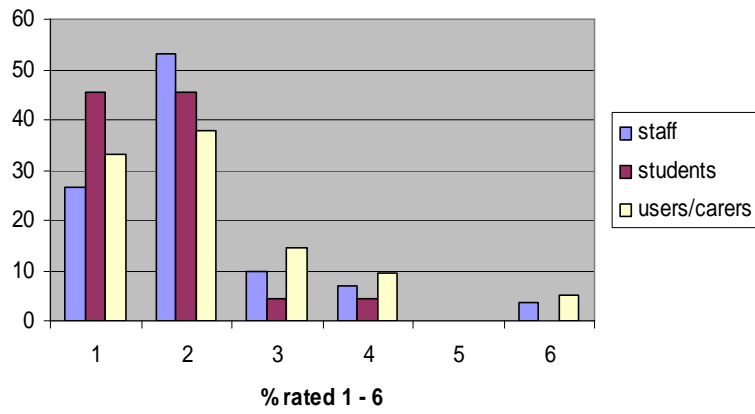




Question 2: Being Down to Earth



Question 2: Listening

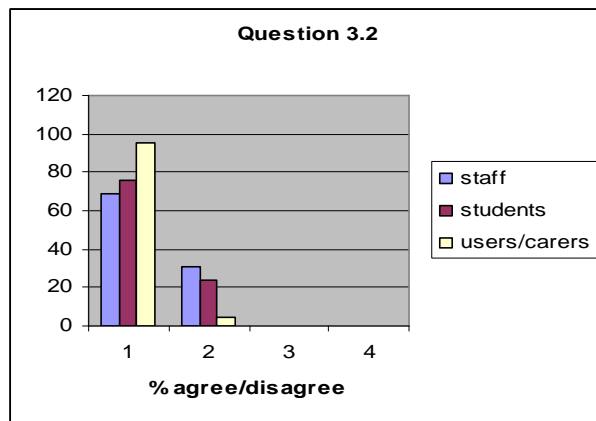
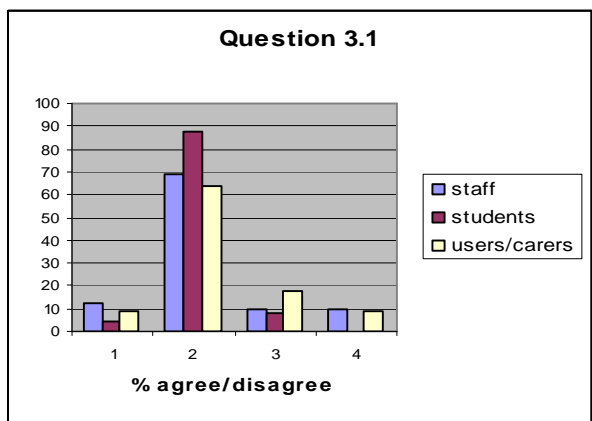


QUESTION 3

For the following questions please indicate how far you agree or disagree with the statements by circling the answer that is closest to yours: (1 = fully agree; 2 = partially agree; 3 = partially disagree; 4 = fully disagree)

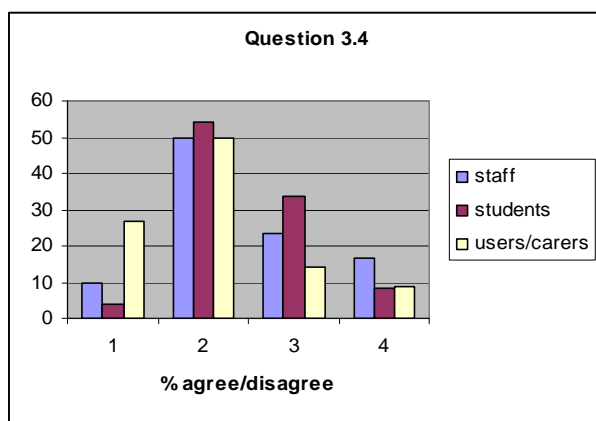
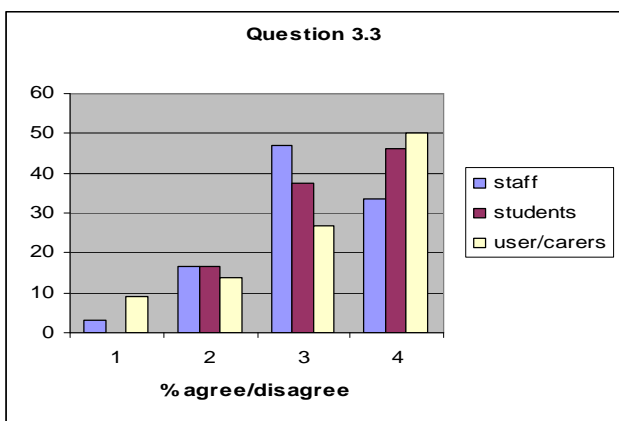
Skilled professionals are able to make accurate assumptions about how common situations will affect the person.

Different health and social care professions should work together to co-ordinate the activity around what is convenient for the patient/service user and carer.



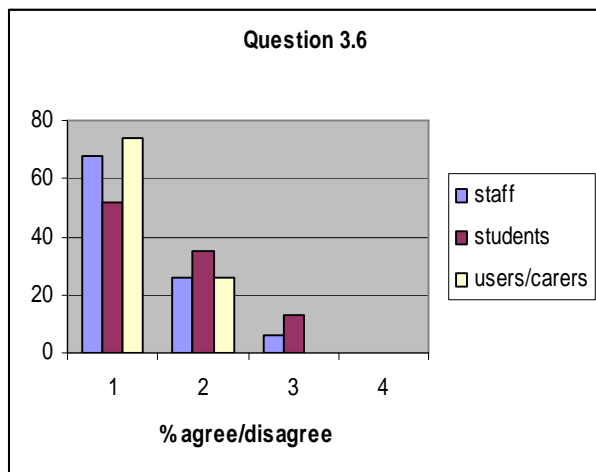
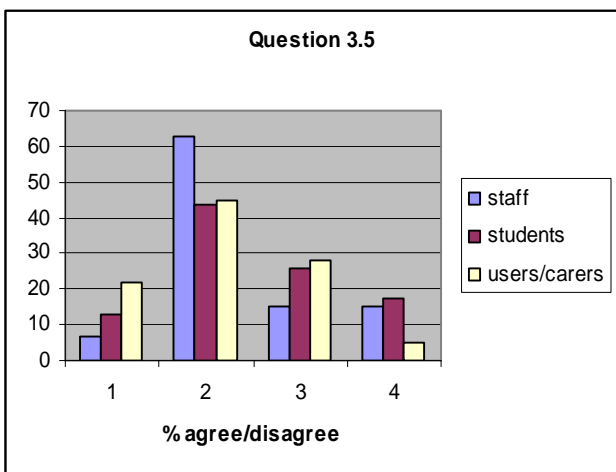
Getting the job done is more important than trying to explain everything to the patient/service user and carer.

Rules get in the way of professionals being creative and taking therapeutic risks.



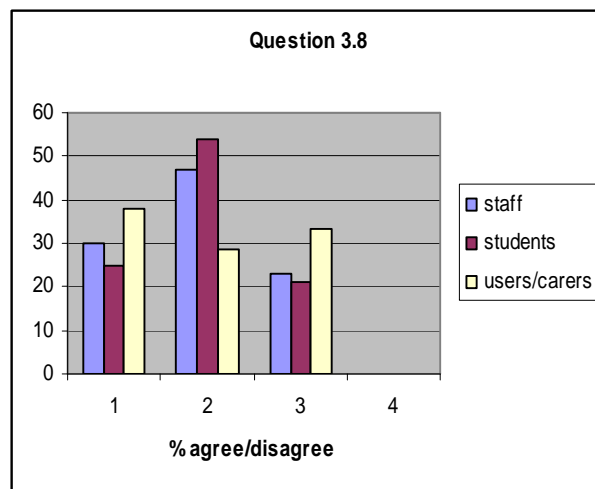
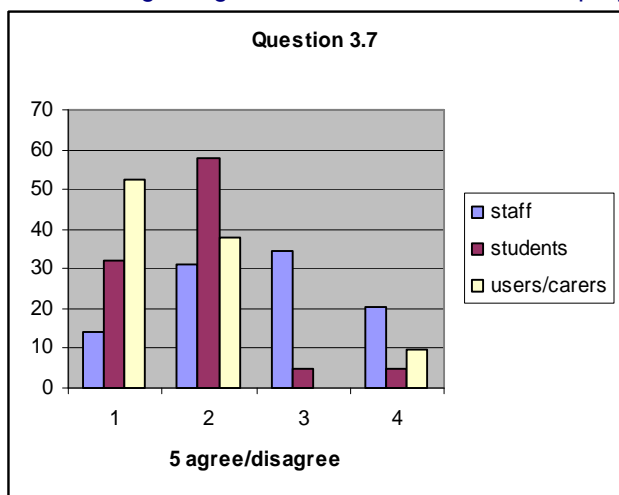
In practice professionals don't have time to focus on the patient/service user and carer as a person.

It is acceptable for a professional to admit not knowing the answer to a problem as long as they have shown empathy and understanding.

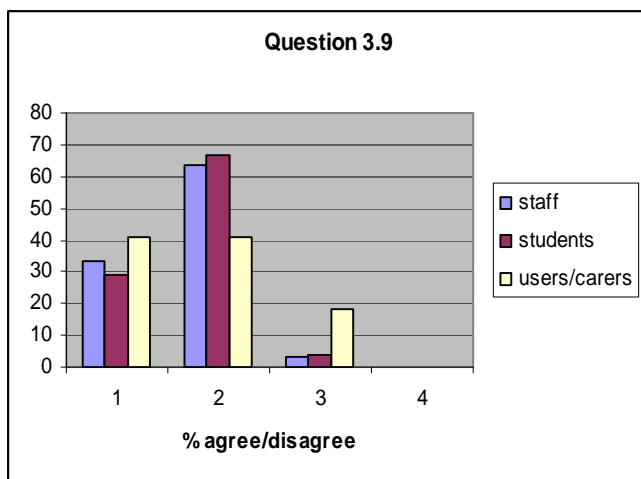


It is as important for patients/service users and carers to see handwashing being done as it is for it to be done properly.

Professionals check out their assumptions with patients/service users and carers about their needs.

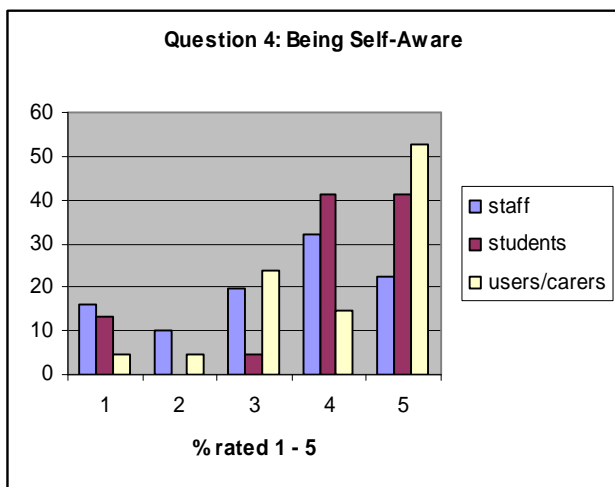
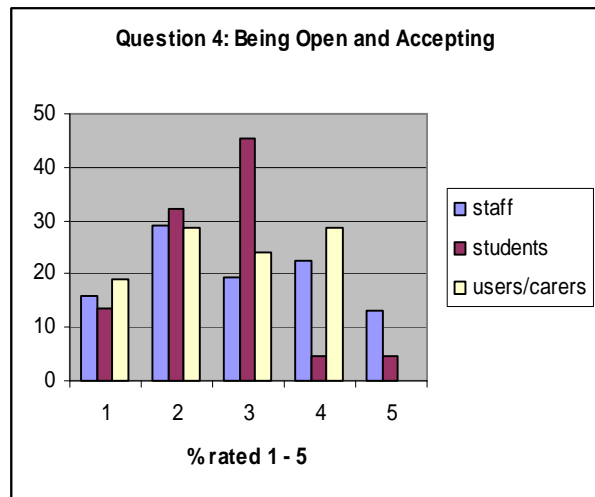
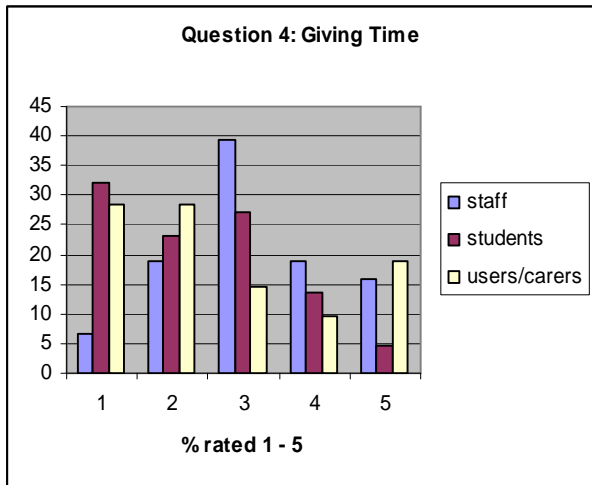
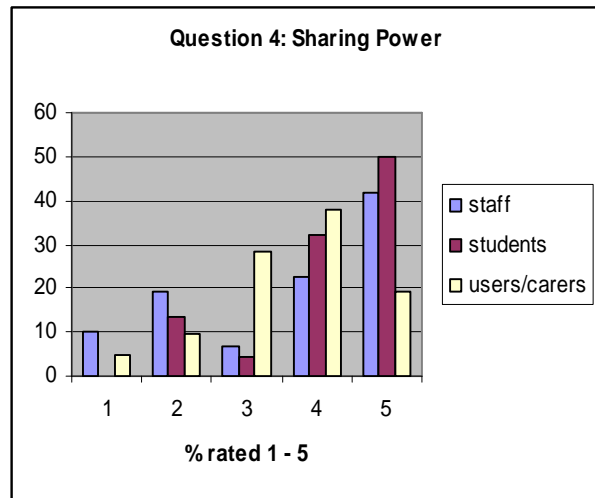
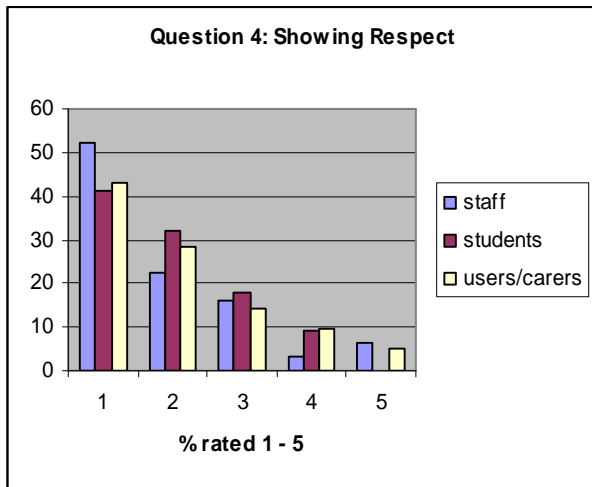


Professionals recognise that a person's need for independent decision making may fluctuate.



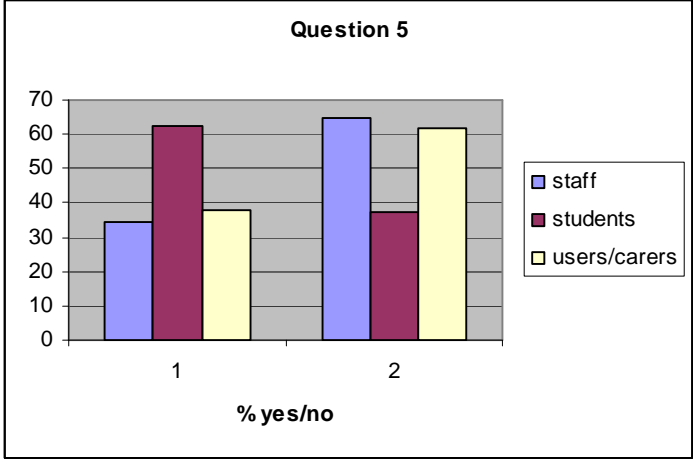
QUESTION 4

This question relates to the relationship between professionals and patients/service users and carers. Please rank the behaviours opposite where 1 is the most important and 5 is the least important:



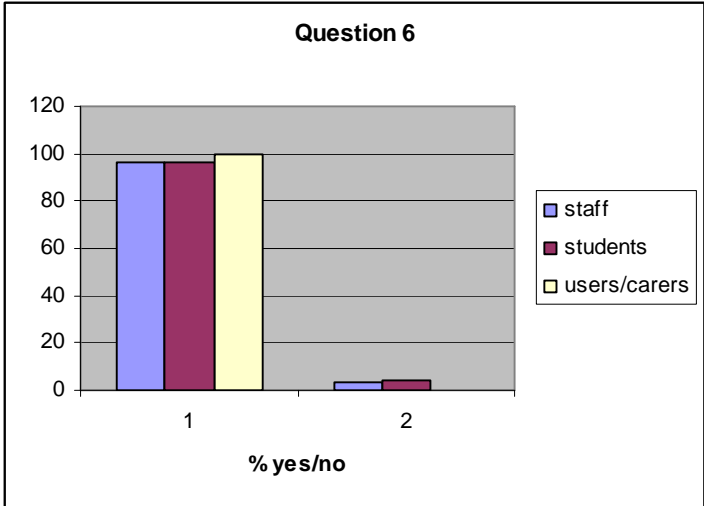
QUESTION 5

**It is important for professionals to behave in a way that marks them out as different from patients/service users and carers:
(1 = yes, 2 = no)**



QUESTION 6

**Professionals should check if a person can or cannot understand what is being discussed:
(1 = yes, 2 = no)**



QUESTION 7

Do you think personal health and social care records should be:

- Kept by the patient /service user or carer (1)**
- Kept mainly for use by the professional (2)**
- Kept by the professional but always available for the patient/service user or carer to add comments (3)**

