User Involvement

Toolkit for User Groups

How to effectively involve patients and the public in User Groups.

Updated: July 2017  Next review: July 2018
Approved by PCEG and IHUG
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A TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC

1 Introduction

This toolkit has been designed to enable members of staff to involve patients and the public in user groups and other involvement opportunities such as user group membership, service development and feedback. It can be used as a reference document to ensure that the needs of those attending have been considered and that people's time is used effectively and objectives achieved.

The successful involvement and engagement of patients, their family/carers and the public correlates closely with how well The Ipswich Hospital NHS Trust (the Trust) has put in place practical support structures.

Patient and Public Involvement (PPI) should be welcomed, valued and recognised as part of the changing culture of the NHS. PPI continues to develop at the Trust, and already there is growing evidence that involving patients, their family carers and the public has brought about improvements to services and the overall patient experience.

2 Patient and Public Involvement (PPI)

There are both national and local strategies and legislation, which require professionals to engage actual and potential users of local services in making decisions at both an individual and collective level. For details please contact the Patient Experience Office on ext 1101.

Successful patient and public involvement is not always easy to achieve. It requires time, commitment and cultural change to overcome the barriers that often exist. However, evidence confirms that there are benefits for both the people who use health and social care services and other related services and for those who provide them, such as:

- Better quality and more responsive services;
- Better outcomes of health and better health for the population;
- Reductions in health inequalities;
- Greater local ownership of health and social care services; and
- A better understanding of why and how local services need to change and develop.

Involvement can range from being consulted about treatment and care or local issues; being informed about a service; taking part in a survey or interview; joining a user, focus, support or specific project group to being consulted about a major plan or development.

3 The Ipswich Hospital User Consultative Framework

The Trust has, over the last few years, built up a successful number of user groups involving patients, their carers, local voluntary/statutory organisations and community groups.
User groups that are now established at The Ipswich Hospital include:

- Cancer Services
- Cardiology
- Children and Young People “Voice for Change”
- Diabetes
- Endoscopy Services
- Eye Clinic
- Hearing Services
- Hotel Services
- Ipswich Inflammatory Bowel Disease (IBD) Patient Panel
- Learning Disability Expert Patient Group
- Musculoskeletal Action Group
- Maternity Services
- Older People
- Pain Management
- Parents Group
- Readers Panel
- Stroke Services

- The Ipswich Hospital User Group (IHUG) – The chair of or a representative from each of the above user groups sits on IHUG.

(See Appendix 1 – The Ipswich Hospital NHS Trust User Consultative Framework)

4 What is a User Group?

User groups:

- Provide a platform for people to reflect on or represent the views of the wider community in co-producing services
- Involve patients and the public in shaping NHS services to meet the needs of individuals and the local community
- Ensure that the services the Trust provides reflect the needs and views of the people who use them
- Enable people to share good practice and raise areas of concern
- Help to build better working relationships and networks with local communities, the voluntary/statutory sectors and with individuals
- Positively influence change and actively engage people in helping to develop services, meet standards and provide information

These groups can consider a wide range of issues including:

- Specific issues of interest/concern to their patient group
- Operational issues
- Issues raised through patient surveys/questionnaires
- Local/National frameworks or standards
- Research and development
5 Who can be Involved in a User Group?
• Individual patients and service users
• Relatives and carers
• Members of the public with relevant expertise or interest
• Members of relevant patient groups, self-help groups and voluntary organisations
• Members of local community groups or organisations
• The Ipswich Hospital NHS Trust representatives
• Clinical Commissioning Group representatives
• Social Care Services representatives

Service users offer their time to:
• Share their experiences of the services they have used
• Give ideas and suggestions on how services could be improved
• Share ‘good practice’ and what the organisation does well
• Help the Trust to plan and make decisions about the services it provides
• Bring an independent user perspective to the design, improvement and delivery of services and service plans.

These people can bring many different perspectives to a user group, in terms of experience, interests, knowledge and expertise.

As a patient or carer they will have expert knowledge of living with or caring for someone who has a particular disease or condition. They will know how it affects their everyday life, will be able to share the bigger picture and have the experience of a variety of services and/or organisations.

As a member of a local community group or voluntary organisation, they will have specific insights into the needs of, or quality of service provided to, a particular group such as, people with a disability, older people or people from black and minority ethnic communities.

6 User Groups are not ...
• The place to raise individual complaints about staff, services, treatment etc. Individuals should be informed of the NHS Complaints Procedure and given contact details for the Patient Advice and Liaison Service (PALS).
• Required to fundraise but there is no objection to an individual member using his or her own contacts to raise funds for a group project. The Trust would expect a more general request for project funding to be handled by the Trust lead for the group. Monies raised would be held within Ipswich Hospital Charitable funds and disbursed in accordance with fund rules.
• The place to raise issues about services, departments etc outside the remit of the group. Any issues, concerns should be raised with the appropriate Trust lead.
• Just information-passing groups. They should have agreed terms of reference and achievable action plans to develop services at the hospital.
• A token gesture.
7 The User Consultative Framework Terms of Reference – User Groups

(See Appendix 2 – Example of Terms of Reference for User Groups)

The User Consultative Framework Terms of Reference were agreed by the Trust to give guidance in the development of the framework and setting up new user groups at the Trust.

It is important that each group has its own individual and agreed Terms of Reference, so that all the members of the group understand and are clear about the purpose and aims of that particular group.

The Terms of Reference can also include relevant directives and standards such as, National Service Frameworks, NHS initiatives and national and local development plans and policies.

Terms of Reference should be reviewed on a regular basis and changed as the group develops.

8 How do I set up a User Group?

The division/department will need to agree who is going to be the lead staff member for the group and allocate time for that person to undertake the role and responsibilities of the user group Trust lead. This person will need to be able to support, facilitate and take issues forward on behalf of user group members (see Appendix 3 – Guidance on Roles and Responsibilities).

The Trust lead should contact the Patient Experience Office on extension 1101 to discuss the user group and what help and advice is needed to promote and support the new user group.

The division/department will need to provide secretarial cover for all the user group meetings, whether they are during the day or in the evening.

9 Recruitment and Appointment Guidelines for User Group Members

Members should be recent (within the last 12-18 months) users (or carers of a recent user) of services or representatives from appropriate organisations able to represent user experiences.

User group members may find out about becoming involved in a number of ways:

- Via an informal approach from an existing group member or member of staff
- Through an event such as an open day or coffee morning
- Via a formal application – completion of an Expression of Interest form.

The prospective member will have to complete an Expression of Interest form and other paperwork available from the Patient Experience Office.

Patient Experience Office (C365)
The Ipswich Hospital NHS Trust
Heath Road, Ipswich IP4 5PD
Tel: 01473 702101
email: pam.talman@ipswichhospital.nhs.uk

The forms should be returned to the Patient Experience Office. The Patient Experience team/coordinate will review the form initially to ensure it is an appropriate application for a particular group.
The form will be forwarded to the appropriate chair who is then responsible for interviewing the prospective member and deciding if they are suitable to join the group. This should be done in conjunction with the Trust lead.

The Patient Experience lead can provide support and additional guidance on the interviewing and selecting of members.

The interview should be informal and cover:

- The background and aims of the group – including the Terms of Reference and an overview of the group structure, meeting times/dates, confidentiality and link with the Ipswich Hospital User Group (IHUG)
- An overview of what they can expect from the Trust – role of Trust lead, paying expenses, training etc, role of Patient Experience lead
- An explanation of what will be expected of them – regular attendance, participation etc
- Additional requirements – Do they need an interpreter (BSL, Language Line) to enable attendance and participation? Do they need transport to be arranged? Hearing loop? etc
- What are their particular areas of interest and background?
- Any questions they may have

The Patient Experience coordinator should be informed of the outcome – they can then provide any additional information they need before they start attending the group.

10 What are the Roles and Responsibilities of Those Involved?

(See Appendix 3 – Guidance on Roles and Responsibilities)

The Trust lead and other members of the group must understand what is expected of them, the boundaries and the commitment and time required to undertake specific roles in the group.

The Trust lead must attend user group meetings or, if unable to attend, arrange for another senior member of staff to deputise in their absence.

It is important that everyone is clear about their role in the group, as no single person can represent the views and needs of the many diverse groups who make up a patient population. For service users, this area can be quite difficult for some people to grasp, as it raises issues about who they are actually representing, their own personal experiences or the wider community’s?

A member of a user group may decide to focus specifically on feeding in the views and concerns of a support group, a community group, sheltered housing complex or their own personal experience. Members must make it clear if they are their own experiences or those of the network they are drawing their views from and when the experience happened.

It is important that people who join a user group are encouraged to share their experiences and views and that all the members of the user group take responsibility in enabling them to do this.

Members and Trust staff must abide by the user group’s Terms of Reference.
## Remember the four Rs

| Remit | o Does the group have clear Terms of Reference?  
o Does everyone have a copy?  
o Has the meaning been discussed so that everyone has the same understanding of what they are there to do?  
If not, people may be ‘travelling’ in different directions and working at cross-purposes. |
|---|---|
| Role | o Is each member clear about his/her particular role?  
o What contribution does each person think he/she is able to offer?  
o What do members think each others' roles are?  
People may make assumptions about the roles of the different group members based on the professional's title, the individual, the group or voluntary organisation that the person belongs to. Does this mean that he/she is a representative of an organisation or are they bringing their own individual perspective to the discussion?  
**It is important to check this out so that everyone is clear.** |
| Relationships | o Does the group feel like a working team?  
o Do people share a common purpose and goals? Have they ever been discussed?  
o Do you know each other as people, or are you strangers bound by your roles?  
It will make a difference to how open and honest people are able to be about the issues they are discussing and may well influence the way decisions are made. |
| Responsibilities | o What is the group responsible for and to whom? (See the Terms of Reference)  
o Is the group clear about issues of responsibility, or is it all left to the chair?  
o Does the whole group take responsibility for seeking user views, putting items on the agenda and ensuring that members have sufficient information for discussion and decisions?  
o Is the group clear how decisions that they make are fed into the wider change agenda within the Trust?  
If this is not clear, it might be helpful to do a mapping exercise to see where the lines of communication from the group go. How does the user group fit in with other groups and committees which are also working in the area of PPI? |
11 The Planning Meeting

Before starting a user group there should be a planning meeting. The Trust lead should discuss with the Patient Experience lead which Trust staff and other organisations should be approached to join the user group.

If the Trust lead has been working with patients and their carers on any specific projects, support groups, surveys etc then it would be beneficial to involve them in the planning of the new user group.

Contact the key individuals and invite them to a planning meeting to share their ideas and thoughts about establishing a new user group and the best way to promote it to reach the people who use the various services.

Planning Meeting – Agenda

You may wish to discuss items, as suggested below, so that everyone is clear about the purpose of the user group, the roles and responsibilities of those involved and the standards the Trust expects in developing PPI.

Suggested areas to discuss:

• Trust lead of the group
• Purpose of the group
• Roles and responsibilities
• Membership
• Promotion and publicity
• Secretarial support
• Finance
• Action plan

The user group will need to decide ways in which it can be promoted to encourage new members.

Some of these items may need to be discussed again at the first and second meeting of the user group so that all the members are involved in the development of the user group.

Suggested Agenda Items:

1 Ground rules
2 Purpose of the group
3 Format of the group (day/date/time/venue)
4 Membership and chair
5 Terms of Reference
6 Travel/Expenses
7 Health and safety
8 Promotion
9 Action plans
Ground Rules

It is important that members set up ground rules to enable and support each other to participate fully in the user group. It is good practice to come back to these ground rules from time to time to remind members what they have agreed or to give an opportunity to add other comments/suggestions.

Some examples from established user groups:

- Members should be encouraged and supported to share their experiences/views of services that they have used.
- Members should respect other people's views and comments and not be judgemental about other's contributions.
- Members should allow each other time to speak, as some people may not be used to speaking in a group/committee situation or they may have a disability, which affects their speech etc.
- Confidentiality – issues, comments, views should not be discussed outside the meeting, unless members agree that they can be shared or minuted.
- If you do not understand what has been said, ask the person to explain again more clearly.
- No abbreviations... No jargon...
- Check at the end of the meeting how people found it.
- Have fun!

Promoting the New Group

The Patient Experience Office can assist in various ways to promote the user group. However, the user group needs to be fully involved in how and where they would like it to be publicised.

12 Expenses

Payment of expenses is very important. It ensures that potential members are not excluded, for example: due to low income, if they are carers or if they have to travel long distances to attend meetings. Members are also giving up their time to attend meetings and should not be expected, in effect, to donate money as well. The Trust is committed to support members to attend meetings, workshops, training, conferences etc.

Information about claiming expenses is available from the Patient Experience Office.

13 Transport

Service users will be encouraged to make their own transport arrangements where possible and mileage or bus fares will be reimbursed if claimed by prior agreement. Members will need to register with the Patient Experience coordinator for expenses.

For those members who attend the meetings at the hospital by car – a car park pass is available, which enables free parking for the duration of the meeting. This will be sent to the member before the meeting.

It is the responsibility of the secretarial support to issue the car park passes.
14 Interpreters and Special Equipment

If a member needs an interpreter, including sign language, or a personal hearing loop system etc, the Trust lead should contact the Patient Experience Office who will make the necessary arrangements.

15 Health and Safety

It is the policy of the Trust, so far as it is reasonably practicable, that the health, safety and welfare of members is not exposed to any avoidable or unacceptable risks. The health and safety of members of the user group is the responsibility of the Trust lead, including directing people to safety in the case of a fire or an emergency evacuation of the building.

16 Booking Venues

The Trust lead/secretarial support is responsible for venue booking.

Always make sure that rooms/venues are booked well in advance. Providing a map is also helpful if people do not know the hospital very well. Always make sure that members have a contact number to call in case they cannot attend the meeting – this should normally be the secretarial support.

Ensure rooms are accessible for those with a disability. Rooms off-site should not normally be booked, unless by prior agreement with the Patient Experience lead.

17 Training and Support

User group members often have personal experience of a disease, condition or using health and/or social care services. Some people are used to committees, groups, meetings etc, but some have never been involved in situations like this before.

Training can be provided to support individuals' involvement – contact the Patient Experience lead for further information.

18 Equal Opportunities

The Trust is committed to preventing discrimination and stimulating equality of opportunity. All employees and volunteers are expected to comply with the Equal Opportunities Policy and to ensure that it is implemented.

- Throughout the Trust it is recognised those involved in PPI play a very important role and contribute to the Trust’s success.
- The Trust actively seeks to encourage people to become involved in patient and public involvement regardless of gender, sexuality, marital or family status, disability, age, race, colour, nationality, ethnic origin, creed or religion, faith or belief.
- The Trust requires all employees and service users to respect the rights and dignity of others. The Trust fully embraces the zero tolerance approach towards violence, verbal abuse, harassment and discrimination and will not tolerate breaches.
- The Trust is committed to protecting its independence and privacy.
19 Insurance

User group members must sign a Participation Agreement. This will ensure that they are indemnified by the Trust for any work undertaken as part of the Participation Agreement on or off the hospital site.

20 Data Protection Act 1998

The Data Protection Act 1998 governs the way in which the Trust collects and uses personal data.

Any information about an individual must be kept confidential and not passed on to any other member of staff, without that person’s permission. Any paper information must be kept in a locked cabinet.

21 Freedom of Information Act 2000

The Freedom of Information Act 2000 aims to ensure that public authorities, such as the Trust, are open in the way that they conduct their business. In compliance with the Act, the Trust has developed a Publication Scheme, which details all the information that it routinely publishes. This includes minutes and notes of meetings. User groups will need to agree how they record members’ names under attendance/apologies and abbreviate people’s names mentioned in the minutes.

22 Conflicts of Interest

There may be times when involving patients, their family carers and the public with certain projects may raise issues around conflicts of interest with the individual or their family members.

People who become involved with PPI will be asked to register and declare any activities/interests which could cause a conflict of interest.

The following are examples of possible conflicts of interest:

• An individual involved in consultation or through a user/project group and may be asked to make recommendations for structural improvements to a ward and a relative is a builder who may tender to make these improvements.

• An individual works for a publishing company and the user group is looking for someone to publish a leaflet.

• An individual is working on a project, which is looking for voluntary sector partners in the community and they work with a voluntary organisation, which is a suggested partner.

A conflict of interest does not automatically mean that they will be unable to take part in discussion or decision making, but the Trust has to be open and fair about what influences its decision making.

If members become involved in projects where companies tender for work and they have a conflict of interest, it is essential that it is declared, so neither the person or the Trust faces potential legal action by a third party.

Contact the Patient Experience Office for more information.
# 23 Monitoring and Evaluation

It is important that the user groups have regular reviews to monitor for example:

1. Membership  
2. Equal opportunities  
3. Access to the group  
4. Terms of Reference  
5. Action plans  
6. Achievements  
7. Promotion  
8. Information

This will enable user groups to develop and enable new people to join and share their experiences, comments and views.

# 24 What Problems Might I Experience?

The following information may be helpful to staff who are currently involved with an established group or are in the process of setting up a new user group or project group.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>POSSIBLE SOLUTION</th>
</tr>
</thead>
</table>
| User group members may:  
- feel reluctant to get involved  
- question how these groups will be able to influence change  
- see themselves as a token gesture to meet the requirements of PPI  
- wonder if the Trust will listen and act on the issues raised  
- wonder if the group has any real power.  
| Ensure that your Terms of Reference are clear and the group understands the purpose and aim of the user group.  
Review the membership, especially the seniority of health professionals on the user group to take issues forward or make decisions.  
Review agenda and minutes. Make sure they include the salient points, actions to be taken, who is responsible for actions and feeding back.  
| Lack of resources  
| Ensure that time is allocated to enable work of the user group to be completed and that administration support is provided.  
| Ensuring effective inclusion and equality may be difficult, for example: reaching and supporting minority ethnic groups, carers, older people, people with learning disabilities etc.  
| Review membership and access to the user group eg venue, time of meetings etc.  
Look at ways in which hard to reach groups can be reached, through contact with local organisations, voluntary groups, community leaders etc.  
Visiting groups, community meetings, questionnaires.  |
<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>POSSIBLE SOLUTION</th>
</tr>
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<tbody>
<tr>
<td>Similar groups may already exist or are being developed.</td>
<td>Research what is available in the local area to prevent duplication and wasting valuable time and resources.</td>
</tr>
<tr>
<td>The same people and organisations get involved in user groups/more than one user group.</td>
<td>Agree Terms of Reference and the period of time people can be a member of a user group to enable new people to join along with new ideas and feedback.</td>
</tr>
<tr>
<td>Some people who attend groups only have one agenda, which may jeopardise the relationship and working of the user group.</td>
<td>Review membership and training needs. Discuss the individual concern outside the user group and how it may be affecting development. Support concern by information, signposting, PALS, complaints procedure etc.</td>
</tr>
<tr>
<td>User groups may be too big and difficult to manage or too small and command little interest or credibility.</td>
<td>Agree Terms of Reference and maximum number of members for the user group. Set up sub-groups for certain pieces of work. Publicise the user group to try to attract members or look at other ways of getting feedback from service users.</td>
</tr>
<tr>
<td>User groups can be confused with focus and support groups, which have different aims and objectives.</td>
<td>Make sure your user groups role is clear and separate from focus/support groups.</td>
</tr>
<tr>
<td>Some members do not attend meetings.</td>
<td>Review membership.</td>
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<td></td>
<td>Ask those who don’t attend why they don’t attend.</td>
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<td>Encourage deputies or substitutes, if appropriate.</td>
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<td></td>
<td>Review the time and place of meetings.</td>
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<tr>
<td></td>
<td>Develop roles and responsibilities.</td>
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<td>Promote claims for expenses.</td>
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<td>Consider if information needs to be provided in different formats.</td>
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<td></td>
<td>Consider if team building activity may help a group to develop.</td>
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</tbody>
</table>
25 Best Practice when Involving Patients, Their Family Carers and the Public

The following points have been suggested by service users who are involved in PPI at the Trust and with other organisations:

1 Good Communication

• Be clear about the task – this will enable individuals to make an informed choice about whether they want to participate.
• Be clear about the basis for involvement – are you looking for a personal perspective or do you need people who can consult with their peers or organisations to offer a ‘broader’ view?
• Users/Carers need to be greeted. Ensure that someone meets them at reception or inform the receptionists where the meeting is being held, so that they can direct people.
• Briefing papers, minutes etc should be written in easily understood English, without jargon and abbreviations.
• A telephone/email reminder is often useful to ensure that professionals, staff etc invited to the meeting remember to attend.
• Don’t use jargon or abbreviations during meetings.
• Make sure members understand what is being said. Enable and empower them to feel comfortable about asking for points to be repeated or explained.
• Be sensitive to cultural and/or language needs. Book an interpreter (language or sign) or any special equipment such as a loop system.
• Make sure that people know whom to contact in case there is a problem or if they require more information.
• It is important that members know the names of other members attending similar groups and that a support framework is established. **It is very important that members are in agreement for you to give out personal details.**
• Evaluation events are a very good way to bring all members together to share good practice and lessons learnt from successes and failures.

2 Be Aware of the Barriers

• Individuals may be unwell and not able to attend every meeting.
• Recognise that people’s abilities and understanding may be different and find ways to support, include and empower all user group members.
• Individuals who care for others may have difficulties in attending meetings.
• Be aware of accessibility, including timing, for example around religious events.

3 Be Honest and Open

• Let the user group set its own ground rules and review these from time to time, so that everyone included is working together as equal partners.
• Value individuals’ involvement, views, comments and suggestions.
• Listen and respect what is being said – be aware that emotions may run high.
• Don’t patronise or be judgemental.
• Admit mistakes.
• If difficult decisions have to be made, be honest and open about them.
4 Support People

Members and their carers need to be valued, trained and supported, for example: prompt and appropriate expenses payments, access to training, being respected and taking their individual needs into account.

- Make sure that individuals are reminded about claiming their expenses and that a car parking pass is sent well in advance of the meeting.
- Check that there is good access for people with a disability, for example: parking/transport arrangements, the venue, toilets and lifts.
- If you are asking members to share personal experiences, think about how this may affect others in the group, particularly if the member has had a bad experience. How can you use their experience, good or bad, in a positive way to improve services or share good practice? Be prepared for different reactions from individuals in the group. Staff and service users may have different views and ideas. How will you deal with this in a professional manner and how will you support those sharing their experiences?
- Encourage individuals to attend personal development training to build on their knowledge, confidence and skills.
- Do not let dominant individuals take over the group. You may need to discuss this with the person outside of the meeting. Remind the group of the agreed ground rules.
- Inform members about the emergency exits and where the assembly points are in case of a fire or major incident.

5 Arranging Meetings

- Be creative, inclusive and sensitive to the needs of the members.
- Give plenty of notice, and details about the meeting: date, venue, time etc. Include a map.
- Try not to cancel meetings. Members will probably have to make arrangements to enable them to attend a meeting. It will not always be easy for them to re-arrange their diaries.
- Time the meetings with care – not too early or when people may need to collect children from school etc. Consult with members to find the best times.
- Introductions are very important and name cards are also useful.
- Make sure that service users understand their role and the roles of other members.
- Make sure members have all the relevant, user-friendly and clear information required for the meeting and ask members how they would like to receive information.
- Consider the length of the meeting and provide breaks if required.
- Papers tabled at meetings should be for information and discussed at future meetings if required. Don’t overload members with papers.
- The Trust lead and the chair agree the agenda for the next meeting. Try not to have too many agenda items, be realistic.
- The minutes of the meeting are a record of the proceedings. They should be a brief report of what was discussed, agreed and the action points.
- Allow sufficient time between meetings for people who use services to consult with their peers or their organisations.
- The Trust lead should contact the responsible individuals to check that action points have been followed-up.
Appendix 1

The Ipswich Hospital NHS Trust
User Consultative Framework

- Stroke Services
- Readers Panel
- Cancer Services
- Cardiology
- Children and Young People ‘Voice 4 Change’
- Diabetes
- Endoscopy Services
- Eye Clinic
- Hearing Services
- Hotel Services
- Inflammatory Bowel Disease (IBD) Patient Panel
- Maternity Services
- Learning Disabilities ‘Expert Patient’
- Older People
- Pain Management
- Parents Group
- Musculoskeletal Action Group
- Maternity Services
- Maternity Panel
- Learning Disabilities ‘Expert Patient’
- Inflammatory Bowel Disease (IBD) Patient Panel
Appendix 2

Example Terms of Reference for User Groups

1 Terms of Reference

The User Groups will:

• Be involved in the development of service policies and procedures that affect patients and the public
• Assist the Trust in developing and monitoring local and national standards
• Work with the Trust in seeking the views of patients and the public about specific services that the hospital provides
• Provide a user perspective in the development of the Trust’s service plans
• Consider patients’ and public feedback, highlighting good practice and making recommendations for improving services for patients and other service users
• Continue to develop links with other voluntary/patient groups
• Work within the Trust’s policies, procedures and guidelines

2 Skills and Interests

Members of the User Groups will be able to:

• Express the views of service users, for example, individual/local need, expectations and concerns
• Share their personal experience or the experiences of other people who use the Trust’s services
• Work effectively with other members
• Communicate with a wide range of individuals
• Act as a link between the User Groups and service users, including voluntary organisations and groups
• Contribute as an individual or as a representative of a group in the development of services, plans and policies that affect patients and the public
• Be actively involved in collecting feedback from service users
• Consider and discuss a wide range of written information
• Share their interest in health matters and promote and support user involvement and consultation

Support will be given to encourage and empower members who may have communication difficulties.

Members will be required to work within the Trust’s policies, procedures and guidelines. Attention is particularly drawn to the following:

Confidentiality – Any matters of a confidential nature, in particular, information relating to the diagnosis and treatment of patients, individual staff information and details of contract prices and terms should, under no circumstances, be passed onto any unauthorised person or persons. This includes compliance with the Data Protection Act 1998, and any breach of confidentiality, will result in membership of a user group being immediately terminated.

Copyright – Members of the Readers Panel are required not to copy any of the patient information that they receive to check, or distribute to any other individual, group etc.
3 Membership

- User group members must be resident or work with people in the Trust’s catchment area and be able to attend meetings.

4 Meetings and Attendance

- It is expected that meetings will normally take place on a bi-monthly basis. Members will decide if other meetings need to be arranged depending on the importance of issues to be discussed.
- Members will decide appropriate days/times and venue for meetings, to enable as many groups/organisations/individuals as possible to be represented. Members will agree these at the first meeting and annually thereafter.
- The chair, or designated person, will become a full member of IHUG and will attend those meetings as a representative of their User Group (see Appendix 3).

5 Financial Support

Members will not receive any salary or attendance allowance. However, the following expenses will be reimbursed, subject to prior agreement and approval.

- Payment of travel expenses to attend meetings or events organised by the user groups.
- Any out-of-pocket expenses directly related to membership of the Trust user groups.
Appendix 3

Guidance on Roles and Responsibilities

Patient Experience Office

The role of the Patient Experience Office is to:

- Support and offer advice to lead managers and Trust leads in the setting up of user groups
- Be a contact point for service users to find out more information about the user groups
- Assist in the promotion of all or individual user groups through events, presentations, displays, information and networking
- Oversee the administration, nominations and appointments of user group members
- Support the training/educational requirements of user group members
- Build links with the voluntary sector
- Attend user group meetings, where possible or when invited to offer support, provide information and to gain knowledge relating to issues highlighted by the group members
- Produce an annual report with the user groups
- Attend IHUG meetings to support its smooth running

Trust Lead

The main role of a Trust lead is to:

Act as the key link between the user group and the Trust. The lead should have sufficient authority to take action between meetings and should work closely with the chair of the user group, the Patient Experience lead and local management staff to ensure the smooth running of the user group and speedy resolution of issues where possible.

Supporting the group

- New Groups. Arrange initial meeting and agree with the members of the user group how often they will meet, time/day and venue.
- Ongoing Groups. Be responsible for organising the meeting – venue, provision of administrative support (minute taking and distribution, issuing car park passes, expenses forms etc).
- Agree draft minutes and the forthcoming agenda with the chair of the group prior to them being sent to members.
- Attend user group meetings as required or send a senior representative if unable to attend – and then liaise with that representative to address any action points arising from the meeting.
- Take forward action agreed at meetings that relate to the Trust’s management of services.
- Be responsible for reviewing recommendations/suggestions by user group members with Trust colleagues and implementing changes as required or identifying the reasons why proposals cannot be implemented.
- Work with the chair of the user group and members to identify an annual action plan or programme of work for the group, which will provide the directorate with information and support in the review and development of services.
• Organise Trust representation at meetings if required:
  o Clinical director(s)
  o Service manager(s)
  o Directorate staff as appropriate.
• Feed back to user group members where changes have been made and give reasons for those not implemented.
• Keep staff updated and involved in the work of the user group and encourage key staff to attend user group meetings.
• Implement and review annually the agreed Terms of Reference as agreed by the user group.
• Work with the Patient Experience lead to identify voluntary organisations and service users who may wish to participate in user groups.
• Be responsible, in partnership with the Patient Experience lead, for the appointment procedure for their user group, to ensure equity, appropriateness and access. (It is recognised that size of groups may vary.)
• With the Patient Experience lead, establish effective communication channels, to enable the views of local groups/individuals who are unable to attend meetings to be heard and fed into user group forums.
• With the support of the Patient Experience Office, organise induction for user group members and any training needs identified.

The Chair of a User Group (Lay Member)

Tenure
• The tenure of the chair needs to be agreed within the group and written into the Terms of Reference. A tenure of two years is suggested with the option of serving up to a maximum of four years.

Main tasks
• Leadership of a user group to ensure it fulfils its objectives as laid down in its Terms of Reference.
• To work in partnership with senior staff across The Ipswich Hospital NHS Trust in pursuit of the above.
• To become a full member of IHUG.

Main duties
• Provide leadership for the user group and ensure the effective functioning of the group whilst chairing its meetings.
• Ensure the user group complies with its Terms of Reference.
• Set the calendar of the user group meetings and agree agendas for these meetings.
• To chair user group meetings – including:
  o Noting apologies from members unable to be present
  o Ensuring those attending know one another
  o Working through the agenda in a timely fashion to ensure the meeting does not overrun
  o Ensuring everyone has the opportunity to participate.
• Receiving draft minutes to ensure accuracy prior to circulation.
• To work closely with the Trust lead to ensure action agreed at the user group meetings is being taken and ensuring members are informed of progress.
• To take action on behalf of the user group outside meetings in line with agreed policies and procedures and in the best interests of the group.
• To present user group views to Trust managers and act as a communications link between Trust managers and user groups.
• To represent the user group, providing a user's perspective at meetings, functions and other events within the Trust and externally.
• To provide an annual report of user group activity.
• To undertake an annual review, in partnership with the Trust lead and PPI lead of the user group’s role, structure and relationships.
• To be involved with the recruitment of user group members.
• To work closely with the Patient Experience lead to further develop and implement the Trust’s Patient and Public Partnership Strategy and involvement of the local community in the Trust’s activities.
• To become a full member of IHUG, representing the views of the user group:
  o Full members are responsible for ensuring that the IHUG feedback form is completed at each user group meeting and that this feedback form is provided to the Patient Experience Office immediately following their user group meeting. The content of the feedback forms will be discussed at the pre-meeting in order that a consensus is reached on issues, which will be raised at the IHUG meeting.
  o Full members will be responsible for reporting on the discussions at IHUG meetings to their user groups at their next user group meeting following each IHUG meeting. Whilst draft minutes will be produced as soon as possible after IHUG meetings, it is the responsibility of full members to make their own record of key points, which they are to report back to their user group.
  o To nominate a deputy from the membership of user group in the event that he or she is unable to attend an IHUG meeting.

**Person specification**

• Ability to chair meetings – able to organise and run meetings methodically, to time and in a manner that supports full participation by all members.
• Ability to work effectively with all user group members and Trust managers.
• Leadership skills.
• Good interpersonal skills.
• Awareness of conflict management issues.
• Integrity.
• An ability to work effectively as a member of a team.
• Understanding of, and ability to promote, the idea of involving and consulting patients/public in how health services are provided.

**Trust Secretarial Support**

The role of the secretary is to:

• Undertake secretarial and administrative duties to support the Trust lead and the user group in their work.
• Liaise with the Trust lead or chair of the user group on any aspects to do with the organisation of user group meetings.
• Attend user group meetings, as agreed with the Trust lead.
• **User Group Meetings**
  o Ensure that the Trust lead and the chair liaise to set the agenda for meetings.
  o Take the minutes at the meeting. A draft copy should be sent to the Trust lead and chair to check and amend.
  o Ensure that an action log is completed/updated following each meeting.
  o The draft minutes will then be sent out to members with information attached and car park passes as required.
- Ensure a copy of the approved minutes are sent to the Patient Experience Office to be uploaded to Trust website.
- Ensure that travel/expense sheets are available at meetings for members to complete. Ipswich Hospital expenses sheets should be sent to the Patient Experience Office.

- To organise communications between members, by keeping records of user group membership. Ensure that the Patient Experience Office is kept up to date with membership details.
- Assist the Trust lead and chair to organise displays, events or produce any promotional material for the user group, as and when required.
IHUG Terms of Reference

1 Definitions

The Trust – The Ipswich Hospital NHS Trust
Trust Board – The Ipswich Hospital NHS Trust Board of Directors
User Group – A group of patients, carers and staff/external organisations convened under approved Ipswich Hospital NHS Trust User Group Terms of Reference

2 Purpose

To contribute to the continuous improvement of services delivered by the Trust by ensuring that the views of service users are sought, coordinated and fed back to the hospital.

3 Terms of Reference

3.1 To receive reports from User Groups on significant issues in their area of specialism, including both achievements and problems which have not been resolved with the User Group’s Trust lead.
3.2 To maintain an overview of patient and public involvement in the Trust.
3.3 To contribute towards the development of Trust policies and procedures that affect patients and public.
3.4 To work with the Trust in seeking views from patients and the public and in developing links with patient/public/community groups.
3.5 To provide a user perspective in the development of the Trust’s service plans.
3.6 To consider patients’ and public feedback, including the findings of the Trust’s annual patient survey and in-house surveys, highlighting good practice and making recommendations for improving services for patients.
3.7 To develop links with other groups engaged in patient and public involvement.
3.8 To monitor the Trust’s service standards and make recommendations to the Trust Management Team based on experiences, ideas and needs of patients and the public.

4 IHUG Membership

4.1 Full membership:
4.1.1 The full, voting, membership of IHUG will be:

- The Chair of each User Group, or their designated IHUG Representative or when the User Group Chair is also the IHUG Chair, Vice Chair or Chair Designate their nominated representative from their User Group.
- The elected Chair of IHUG.
- The elected Vice Chair(s) of IHUG.
- The elected Chair Designate of IHUG (as and when applicable).
4.1.2 If the Chair, Vice Chair(s) or Chair Designate of IHUG is also a Chair of a User Group, another representative from that User Group shall be nominated by the Chair of that User Group as the IHUG representative.

4.1.3 Each member of IHUG will have one vote, in case of a tied vote, the Chair, or whoever has been elected to chair the meeting, will have a casting vote.

4.2 Associate membership:

4.2.1 The following representatives may attend IHUG meetings:
- Up to two NHS Ipswich and East Suffolk Clinical Commissioning Group patient & public representatives
- Up to two Healthwatch Suffolk representatives
- Suffolk Family Carers representative.
- A representative from each community hospital – Bluebird Lodge, Aldeburgh and Felixstowe
- A representative from the Suffolk Disability & Health Action Group

4.2.2 Associate members have no voting rights.

5 Ex-officio Members

5.1 The following positions have ex-officio membership of IHUG:
- The Chief Executive, The Ipswich Hospital NHS Trust
- The Ipswich Hospital NHS Trust Board Executive Directors
- The Ipswich Hospital NHS Trust Board Non-executive Directors
- The Patient Experience Lead

5.2 Ex-officio members have no voting rights.

6 IHUG Chair

6.1 The Chair of IHUG will be elected by the full members of IHUG.

6.2 The election, if contested, will take place through a secret ballot, which will be co-coordinated by the Patient Experience Lead.

6.3 Any election for Chair of IHUG will be made on the basis of ‘first past the post’.

6.4 Candidates for election as Chair must be nominated in writing by at least two members of IHUG at least one month prior to the date of the election.

6.5 The Chair will serve for an initial period of two years, which may be extended by a further two years up to a maximum period of four years.

6.6 Once the Chair has served eighteen months of their initial two-year period they will declare to IHUG whether they intend to continue for the full four-year period.

6.7 If the Chair declares that he or she intends to continue beyond the two-year period, IHUG will discuss whether they wish that an election with an alternative candidate for the position of Chair is held or if the existing Chair shall continue unopposed for full four-year period.

6.8 If IHUG decides that an election should be held, this decision must be approved by at least two thirds of the IHUG full membership.

7 Chair Designate
7.1 In order to ensure continuity between consecutive Chairs of IHUG, the Chair may be elected six months in advance of taking up the role.

7.2 In this case, during the period between when a new Chair is elected and when he or she takes up the role of Chair, the person shall be known as Chair Designate.

7.3 Once a Chair Designate is appointed he or she shall establish a shadowing and mentoring arrangement with the IHUG Chair during the period until they become IHUG Chair.

8 Vice Chair

8.1 There can be up to two Vice Chairs who will be elected through the same process as that for the Chair.

8.2 A Vice Chair will serve for the same term of office as the Chair and will also have to declare after eighteen months to IHUG whether they intend to continue for the full four-year period.

8.3 If a Vice Chair declares that he or she intends to continue beyond the two-year period, IHUG will discuss whether they wish that an election with an alternative candidate for the position of Vice Chair is held or if the existing Vice Chair shall continue unopposed for the full four-year period.

8.4 If a Chair of IHUG does not serve a full four-year term this will not preclude a Vice Chair serving a four-year term.

8.5 In the event of the death or long-term incapacitation of the IHUG Chair, a Vice Chair shall take over the role of Chair until the due date of the next election. Where there are two Vice Chairs this may be a shared role.

8.6 In the event of a Vice Chair assuming the role of Chair, or the death or long term incapacitation of the IHUG Vice Chair, an election for the vacant role of Vice Chair shall take place as soon as is practicable.

9 IHUG Meetings

9.1 IHUG Meetings shall be held every six weeks, normally at the Ipswich Hospital site and will usually be of two hours duration.

9.2 All reasonable effort will be made to ensure that IHUG meetings are held in venues/rooms which are accessible to all people and information is available in all formats.

9.3 The IHUG Chair shall act as Chair for all meetings at which he or she is present.

9.4 In the event of the absence of the IHUG Chair from a meeting, a IHUG Vice Chair shall chair the meeting.

9.5 In the event of the absence of both the IHUG Chair and Vice Chairs 15 minutes after the appointed start time of the meeting, those present shall elect a Chair for the meeting from those full members present. If the Chair/Vice Chair then arrives they will take over the running of the meeting.

9.6 IHUG meetings will be considered quorate provided at least one third of full members and one member of Ipswich Hospital NHS Trust Board are present.

9.7 In the event of a full, associate or ex-officio member being unable to attend any meeting, they may nominate a replacement to attend the meeting. In the event of a replacement being nominated, the IHUG Chair shall be informed by the member prior to the meeting of the name of their replacement.
9.8 If a full member is absent from more than four consecutive IHUG meetings, IHUG reserves the right to request a replacement member from the relevant User Group.

9.9 Secretarial and administrative support to IHUG will be provided by the Trust.

9.10 IHUG Meetings will not be open to the press or public.

10 Reporting Responsibilities of Full Members of IHUG

10.1 Full members are responsible for ensuring that the IHUG feedback form is completed at each User Group meeting and that this feedback form is provided to the IHUG administration immediately following their User Group. The content of the feedback forms will be discussed at the pre-meeting in order that a consensus is reached on issues, which will be raised at the IHUG meeting.

10.2 Full members will be responsible for reporting on the discussions at IHUG meetings to their User Groups at their next User Group meeting following each IHUG meeting. Whilst draft minutes will be produced as soon as possible after IHUG meetings, it is the responsibility of full members to make their own record of key points, which they are to report back to their User Group.

11 Relationship to the Patient & Carer Experience Group (PCEG)

11.1 PCEG reports to the Quality Committee (a sub-committee of the Trust Board) and its role is to monitor the full range of activities related to improving the patient and carer experience, as part of the governance structure of the organisation.

11.2 PCEG will receive copies of the minutes for information, regular reports from user groups and will receive the IHUG Annual Report.

11.3 IHUG will receive copies of approved PCEG minutes.