Checks, Roles and Windfalls – why is a registration system needed for public involvement?

In entirely informal systems, academic researchers would form easygoing partnerships with people they get to know who have lived experience of the health condition or social challenge that they face. We might hope that these relationships would be characterised by mutual trust, equality and power sharing, so that both the expert by experience and the academic bring their whole selves to the encounter, enriching their individual lives and the quality of the research they conduct together.

Bureaucrats and risk managers enter this sunny world and find hazards everywhere. They are, of course, not the only ones to notice the dangers of unequal power, of deference or abuse, but they bring their belief that such hazards can best be managed by administrative systems. The following tables attempt to work through some of the multiple issues involved in designing an administrative system that facilitates rather than blocks access.

The first step is to list some of the obligations that drive any effort to form a system for involvement. They have been grouped under five subheadings as shown in Table One.

Table One: Formal obligations

	Subheading	Details
1	Rights of the individual	Each person who comes into the organisation as an expert by experience, visitor or guest has a right to be respected, to have the maximum autonomy, choice and control that is practically possible, and to have their right to privacy upheld. Where opportunities for participation arise, people should have fair access.
2	The organisation's mission	The organisation's mission should guide decisions about all its activities, including those involving Public Contributors. Management arrangements support both staff and Public Contributors to achieve alignment between mission, activities and outcomes.
3	Legal and procedural compliance	Regulations designed to manage migration affect the engagement of Public Contributors[1]. The organisation must track protected characteristics to meet its Public Sector Equality Duty under the Equalities Act 2010. GDPR sets out the way in which personal information about Public Contributors is managed properly. Payment arrangements must comply with employment law, welfare benefits and tax regulation.
4	Keeping everyone safe	The Management of Health and Safety at Work Regulations 1999 require organisations to undertake a risk assessment and then minimise and manage risks to meet its duty of care under common law. The HRA expects research sites to obtain reassurance about the competence, character and indemnification of Public Contributors[2]. As far as possible, people should be protected from fire, accident, illness and mental health crisis. The organisation may wish to know who to contact in an emergency on behalf of anyone who regularly enters its buildings.
5	Internal systems	Due diligence obligations require the organisation to create an audit trail for financial transactions. Staff need to stay in touch to let potential and current Public Contributors know about future opportunities for participation and exercise a pastoral duty of care for those with whom they engage.

These five categories are not mutually exclusive, as, for example, while achieving legal compliance (item 3 above) meets the organisation's obligations to outside agencies, it also requires internal systems (item 5) to deliver and monitor this compliance. The section on keeping everyone safe could have been subsumed into legal compliance above, but it seemed clearer to give it a subheading of its own. Nor is this listing collectively exhaustive, as there may be other factors which, from time to time, affect the activities of Public Contributors. These might include duties in relation to prohibiting modern slavery or achieving environmental sustainability. Nevertheless, it is hoped that the structure and contents of Table One capture most of the key themes that should be considered when designing a proper system for registering and involving Public Contributors.

The issues listed in Table One are addressed by the organisational solutions set out in Table Two. Each item in the table may have a broader application beyond the arrangements for Public Contribution, and perhaps apply to anyone entering the building or who has any kind of association with the organisation, but Table Two is focused on the involvement of Public Contributors.

Table Two – Mapping obligations on to system responses

	Obligation	System Response
1	Rights of the Individual	Values based practice reminds staff of their obligations towards Public Contributors. The Research Ethics Committee checks the values and practices that shape the work of research teams.
2	The organisation's mission	An Event badge or Photo ID badge links the Public Contributor to the organisation's work and reputation. The Code of Conduct defines acceptable behaviour for staff and Public Contributors. Reporting to funders and inspection by teaching regulators reminds staff of what is expected in relation to the role of Public Contributors.
3	Legal and procedural compliance	The Public Contributors Register includes identity checking, contact information[3] and information governance systems. Equalities monitoring identifies need for positive action whilst remaining independent of the Public Contributors Register to prevent bias in decision making. The Payment arrangements and reimbursement of expenses systems meet obligations in respect of employment law, taxation and welfare benefits.
4	Keeping everyone safe	Public Contributors provide References, interview and a DBS check where indicated, leading to a Support and risk mitigation plan where necessary. Public Contributors receive Training in safeguarding, information governance and ethics. Induction and Supervision[4] arrangements for Public Contributors and staff mitigate the risks associated with unobserved time and reduce opportunities to abuse others or to steal property or confidential information. Complaints procedures and Insurance cover is in place for times when things go wrong. Individual events take a Register or utilise the Signing In book on Reception and provide Safety briefings (fire procedure etc).
5	Internal systems	The Public Involvement Handbook brings together all the policies and procedures outlined above under the direction of a Public Contributors Advisory Group, reporting to the organisation's Leadership Team. Development support and training is provided to both staff and Public Contributors along with Feedback mechanisms to ensure that the organisation learns from individual and group experiences.

At this point, our attention narrows to the process by which Public Contributors are registered and we consider what kind of personal data is collected from applicants as part of their introduction to the role. This is the admission point that determines who is offered an opportunity to become a Public Contributor, and the point at which any restrictions or limitations in access are likely to have the largest impact.

It is helpful to compare the approach taken by different organisations as this will serve as a benchmark for the practices of our own organisation and may also allow for the possibility of a kind of preferred provider mechanism. Should such an arrangement be negotiated, then anyone who has already completed parallel checks with another organisation would not be required to repeat the process. Table Three sets out the information that a handful of local organisations ask for in their registration system.

Before drawing conclusions from Table Three it is worth noting that some of the organisations described in this table are themselves in flux. The introduction of GDPR in May 2018 and other changes have triggered a review of process in many organisations. The telephone conversations through which these data were collected produced a range of responses, such as:

- *We definitely don't collect that, and here's why.* An example is next of kin information, which some respondents consider to be (i) rarely needed; (ii) suggestive of a controlling relationship rather than a partnership; and (iii) a stigmatising question for isolated people.
- *We don't collect that and perhaps should.* Equalities tracking is an example.
- *We do collect that, but generally after building a relationship* with the person rather than at first contact. An example is the code of conduct, which some respondents prefer to negotiate during early meetings rather than impose from the outset.

It is a notable observation from the data in Table Three that only a few organisations ask for a lot of information from Public Contributors at registration stage. A general remark from one Public Involvement lead was to note that these procedures should be kept to a minimum as they had the effect of excluding marginalised people and were experienced as disproportionate and annoying. Even an organisation that has several fulltime staff deployed on promoting and supporting Public Contribution, does not use these staff resources to collect more information at registration.

Furthermore, respondents explained that some of the obligations to collect data at registration were imposed by external forces, rather than decided internally through discussions between Public Contributors and Public Involvement staff. For example, where Public Contributors are treated as contractors or visiting lecturers, then a definite contract is in place and employment-related procedures must come into play, such as identity verification (to meet Home Office requirements) and DBS checks, as would apply to any other employee or contractor.

Both of our local NHS Trusts use a two-tier system for engaging volunteers that provides a simpler form of registration for people taking up low-risk roles and a more thorough approach that is applied to high trust roles relating to patient contact, thus meeting obligations for due diligence.

It is noteworthy that organisations that collect a small amount of information are not confined to the voluntary sector, but minimal practice is also in use at some centres managed by the NHS or Universities.

Finally here, table three refers to a Staff Host. This is an employee of the organisation who is in close touch with the Public Contributor, understands their role and contribution to a particular project, and provides support and guidance.

Table Three – Which registration checks are made where

Registration mechanisms required	A BRC	NHS Trust 1 Volunteers programme	NHS Trust 1 Involvement Centre[5]	NHS Trust 2 Guest volunteers[6]	NHS Trust 2 full Volunteers
Contact details	✓	✓	✓	✓	✓
Equalities tracking		✓			✓
Payment details[7]			✓	✓	✓
Code of Conduct		✓		✓	✓
References		✓			✓
Staff Host		✓		✓	✓
Next of kin		✓	✓	✓	✓
Induction training		✓		✓	✓
Declaration of offences		✓			✓
DBS	Some	Some			✓
ID verification		✓			✓
Registration mechanisms required	**A user-led research charity**	**An informal research group**	**A user-led group hosted by a university**	**An academic research centre[8]**	**A university Public Involvement Team**
Contact details	✓	✓	✓	✓	✓
Equalities tracking				✓	
Payment details[9]	✓		✓		
Code of Conduct	✓	✓	✓		✓
References					
Staff Host	✓		✓		✓
Next of kin					✓
Induction training			✓		✓
Declaration of offences			✓		
DBS			✓		
ID verification			✓		

While Table Two offers material to help our thinking about the overall bureaucracy, it is not yet sufficiently focused on individual tasks. An examination of the activity of Public Contributors suggests that the contributions of individuals can be described as a mix of the seven core roles which are described in Table Four. These are idealised roles and it is recognised that the majority of Public Contributors will engage in several of these roles rather than remaining confined to a single activity.

As the reader moves down this list, other variables increase in value. Firstly, the level of trust placed in the Public Contributor will broadly increase, as does the risk attached to the role. However, the individual arrangements for specific activities may adjust their relative position in the Table Four, so the sequence is only broadly correct rather than positions being precisely allocated for all circumstances. For example, if the confidential data is merely nominal information and the interview is sensitive, then the interview will involve much more risk. Secondly, as risk and trust increase so there is a corresponding increase in vetting and support arrangements.

Table Four – describing the core roles of Public Contributors

Core role	Description
Review document at home	Remote document review draws in views from people who are too geographically distant to attend meetings, who are unable to leave their home and who have commitments reducing their availability to attend events. This group of Public Contributors will generally be literate and comfortable with managing electronic documents. They may also be research application reviewers, and so bring these insights. However, their contribution can be blended with the offerings made by many others, and decision makers can filter and set aside any unsuitable remarks prior to sharing with anyone else.
Attend conference or focus group	Conferences and focus groups are one-off events deemed to be in the public domain. If the material that is covered is 'commercial in confidence' or sensitive, then it falls into the Committee member category below.
Public speaker	Public speakers have power to influence public perception of the organisation since they can speak spontaneously and be heard by a large audience without prior filtering. This also applies to material which is published on social media. The Code of Conduct sets out the behaviours which are expected in relation to these roles.
Committee member	While Public speakers may be involved on a single occasion, committee members have an ongoing influence on the success of the project and can influence its shape over its lifetime. Agenda items may be confidential to the group.
Interview patients	Some would redefine this role and those below as waged positions. Adjustments may need to be made to such paid roles to make them accessible to some people with lived experience. However, this document proceeds with the view that these roles are legitimate for unwaged volunteers who serve as Public Contributors. NHS procedures consider patients to be vulnerable and insist on vetting arrangements, so there is a process by which suitable Public Contributors may be provided with a Letter of Access, enabling them to interview NHS patients for research purposes. Risk is reduced if an employed academic researcher works alongside the Public Contributor to conduct a 'Two on One' interview[10].
Handle confidential data	NIHR guidance[11] indicates that people carrying out this task do not need DBS checks, but this is considered to be a typing error and the trust involved in handling confidential data is deemed to require careful vetting and support.
Co-applicant	Co-applicants may attend the Trial Steering Committee (that reports to the funder), Data Management and Ethics Committee or Project Management Team. Some may also recruit other Public Contributors, chair meetings and act as the Staff Host. For these reasons, the level of risk and trust is high.

We can now tabulate these core roles against the checks we have identified in Table Three and create a simplified, workable system. Table Five works through the potential registration steps for each of the seven roles and shows how almost all the options can be dealt with through creating two options – Brief Registration and Detailed Registration. These are different in style, as all the items required for Brief Registration need to be collected, while the items included in Detailed Registration vary according to the activities that the Public Contributor will undertake.

People who are new to the role of Public Contributor may wish to utilise Brief Registration if they expect their activities to remain minimal and static, or alternatively complete more of the process in anticipation of receiving a wide range of invitations to contribute in a variety of ways. As the registration process can take some time, it is helpful to begin in good time, rather than find that opportunities are frustrated by delays in authorisation.

Table Five: Introducing Brief and Detailed Registration

Opens the door to…	Brief		Detailed				
	Review document at home	Attend conference, focus group	Public speaker	Committee member	Interview patients	Handle confidential data	Co-applicant
Contact details	✓	✓	✓	✓	✓	✓	✓
Equalities monitoring	✓	✓	✓	✓	✓	✓	✓
Payment details	✓	✓	✓	✓	✓	✓	✓
Code of Conduct			✓	✓	✓	✓	✓
References			✓	✓	✓	✓	✓
Staff Host				✓	✓	✓	✓
Next of kin				✓	✓	✓	✓
Safeguarding and IG training				✓	✓	✓	✓
Declaration of offences					✓	✓	✓
DBS					✓	✓	✓
ID verification					✓	✓	✓

Some projects may decide to vary the details of Table Five a little to respond to their individual circumstances, such as where a 'Public Speaker' is promoting recruitment through presentations to prisoners, and the environment demands a DBS check. Where a real-life role covers several of these idealised roles, the one that demands the most information will, of course, eclipse those entailing a lesser demand.

It is to be hoped that all Public Contributors gain benefits from the opportunity to further scientific knowledge and improve patient care – not least in the realisation that their experiences can be an asset, their contribution is appreciated and that their skills are of value. Some roles bring additional consequences that are called 'windfalls' in Table Six below. This term is used in preference to alternatives such as benefits, privileges or perks, since such terms suggest that a contract of employment and corresponding formal obligation may be in place, which there is not; or that these items are a gracious gift from the organisation to a dependant subject, rather than an appropriate provision to enable the Public Contributor to carry out the role.

Again, Table Six offers no more than a rough framework and the details may vary in response to the circumstances of an individual project or Public Contributor.

Table Six: Windfalls that may accrue to people who take on these roles

Windfalls	Roles						
	Review document at home	*Attend conference, focus group*	*Public speaker*	*Committee member*	*Interview patients*	*Handle confidential data*	*Co-applicant*
Reimbursement of expenses	Not applicable	No – unless indicated	Yes – where (i) funds are available, (ii) the person is a registered Public Contributor and (iii) their claim is countersigned by the Staff Host				
Participation payment	Yes						
Photo ID badge	No		Yes – where the Registered Public Contributor has an ongoing relationship with the organisation sustained over time and support from their Staff Host underpinned by fair reasons				
Keypass to the building	No		Yes – where (i) the Registered Public Contributor has an relationship with the organisation sustained over time; (ii) the Staff Host supports the case for issuing a keypass, underpinned by fair reasons. The pass is to be active in office hours only				
Use of hotdesk in a public space	No	Yes – where approved by Staff Host					
Use of hotdesk – in an open plan office	No		Yes – but only when under the direct 'line of sight' supervision of the Staff Host, but not in their absence. The Registered Public Contributor would normally be carrying out activities that require them to be in the secure office space (such as interviewing, using a computer or handling confidential data). If unsupervised activities are required that involve these high levels of responsibility and trustworthiness, then the person should become a contractor or employee, not a PPI volunteer				
Email address			Yes – where the person is engaged on activity for the organisation that requires the use of email and the Staff Host supports it.				
Access to medical library			Yes – where the person is engaged on activity for the organisation that will be enhanced by access				
Car park voucher	No – this is confined to people who have a contract with the organisation and support from their line manager or contract holder. Such persons may be charged a reduced fee for their vouchers.						
Research passport	No – this is for employed staff only						
Letter of access	No				Yes		No

Table Seven shows how the organisation embeds support for Public Contributors by establishing systems for the consistent delivery and quality assurance of the five duties (Table One) in respect of each of the seven core roles of Public Contributors (Table Four).

Table Seven –System responses to support core roles

Obligations	Roles						
	Review document at home	*Attend conference, focus group*	*Public speaker*	*Committee member*	*Interview patients*	*Handle confidential data*	*Co-applicant*
Rights of the individual	Feedback form shows how ideas are used	Patients Included	Organisational culture that promotes coproduction and active partnership with Public Contributors				
The organisation's activities, mission and impact	None	Event badge	Public Contributors Register, Code of Conduct, induction. Staff Host to provide supervision and development support. Photo ID badge as required				
Legal and procedural compliance	Payment records show requests made, payments offered and received	Health and Safety obligations to maintain safe premises	Equalities monitoring tracks protected characteristics, appropriate information governance systems				
Keeping everyone safe	Staff Host to support Public Contributor and ensure task is matched to skill and capacity.	Event Register. 'Flight attendant' briefing to delegates.	If this includes 1:1 meetings with others – see below…	Reasonable adjustments to ensure meetings are accessible	Training (safeguarding and information governance) and supervision to mitigate risks associated with unobserved time which gives opportunity to abuse others or to steal property or confidential information		Staff Host to support Public Contributor and ensure task is matched to skill and capacity
	Security and emergency services as with any other member of the public	Public Contributors Register to include home address and contact details, next of kin, care coordinator. References and Interview. DBS check where indicated followed by risk mitigation management plan with anyone who has a history of causing substantial risk to others. Insurance cover for public and employer's liability.					
Internal systems	Contact details for future advertising	Financial Records in support of money changing hands and people speaking or acting on behalf of the organisation.					

Local arrangements for each of these items are set out in a Public Involvement Handbook, and specific information is collected via the use of some standard forms, as shown in Table Eight.

Table Eight: Forms mapped on to each role

Forms to be used	Roles						
	Review document at home	*Attend conference, focus group*	*Public Speaker*	*Committee member*	*Interview patients*	*Confidential data handling*	*Co-applicant*
Brief Registration application form	Yes – unless people are otherwise involved.	No – single event only	Yes				
Registration process – reference request	No	No – single event only	No – accepted at face value	Yes – significant risk here, so independent verification is required.			Yes – 'reference' can come from a team member
Understanding your expertise and any support or adjustments required	No	No – single event only	Yes				
Diversity monitoring	No Entirely optional for all and should be kept anonymously						
Code of Conduct	No	No – single event only	Yes				
Bank details payments	No - use petty cash or vouchers unless people are otherwise involved		Yes – where (i) funds are available, (ii) the person is a registered Public Contributor and (iii) their claim is countersigned by the Staff Host				
Claim form for reimbursement of expenses and/or participation payments	No - use petty cash or vouchers for unless people are otherwise involved		Yes – as above				
NHS Model declaration form A or B	No – this is for employed staff only						
Research passport	No – this is for employed staff only						
Letter of access	No				Yes		No

Completed registration may lead to windfall benefits or opportunities. These are often no more than items that are required to enable people to complete the task for which they have become a Public Contributor. They were, of course, set out in Table Six.

Conclusion

This suite of matrices shows how the roles undertaken by Public Contributors can be used to drive the system of checks and the windfall benefits that accrue. It sets out the external obligations and the internal systems required to support effective participation by Public Contributors.

Readers may make different choices at each step of the process set out here, by identifying new categories of activity, responding to different drivers in the external environment and responding with different management, control and assurance mechanisms, but it is hoped that this analysis will help readers develop systems that meet legal obligations and include people irrespective of their need for support.

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[1] A migrant to the UK may commit an offence by working (even if unpaid) without appropriate permission, and the engaging organisation may incur a civil penalty, especially if money is changing hands.

[2] Para 9.16d of 2017 guidance from the Health Research Authority here.

[3] At the request of the Public Contributor, the Register might include the contact details for the person's Care Coordinator and guidance about the circumstances under which the Public Contributor wishes them to be contacted.

[4] The terms 'induction' and 'supervision' are used for clarity, but do not imply that Public Contributors are employees.

[5] This is the light touch involvement used by the Involvement Centre. Where people are involved in more significant trusting relationships, they register as volunteers through the Trust's Volunteer Manager.

[6] Guest volunteers at the Trust do not have patient contact and tend to have short term or even single event involvement. Other volunteers are taken through the full registration process. Any Public Contributors who are regularly involved with projects need to be registered as volunteers.

[7] Some of these organisations engage people as unpaid volunteers and either do not offer reimbursement of expenses or do so via petty cash, so have no need of bank details.

[8] These items appear on the application form for the Community Partners Panel.

[9] Some of these organisations engage people as unpaid volunteers and either do not offer reimbursement of expenses or do so via petty cash, so have no need of bank details.

[10] Advice on these interviews is available as How to involve people as research co-interviewers.

[11] NIHR (2012) *Research in the NHS – HR Good Practice Resource Pack. The Research Passport: Algorithm of Research Activity and Pre-Engagement Checks. Effective from 10 September 2012*, pages 5 and 6, available at https://www.nihr.ac.uk/02-documents/policy-and-standards/Faster-easier-clinical-research/Research-passports/The-Research-Passport-Algorithm-of-Research-Activity-and-Pre-Engagement-Checks.pdf.