# Public participation in research
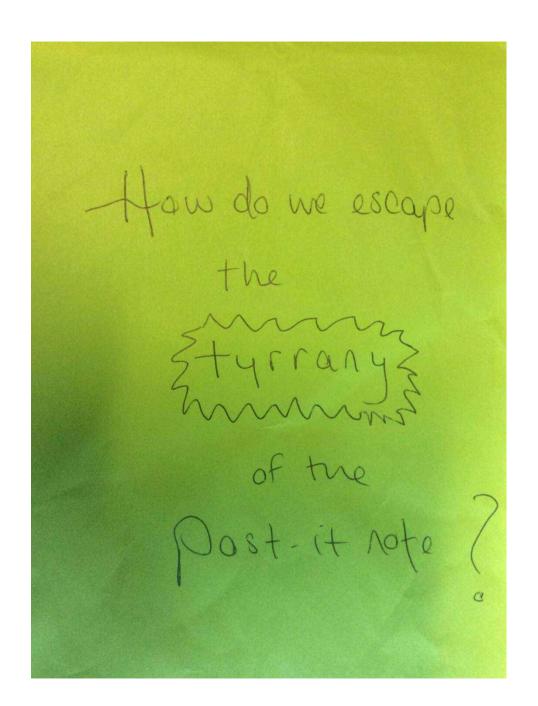
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# · BAD ⚛ SCIENCE ·

## 1. SENSATIONALISED HEADLINES

Headlines of articles are commonly designed to entice viewers into clicking on and reading the article. At best, they over-simplify the findings of research. At worst, they sensationalise and mis-represent them.

## 2. MISINTERPRETED RESULTS

News articles sometimes distort or misinterpret the findings of research for the sake of a good story, intentionally or otherwise. If possible, try to read the original research, rather than relying on the article based on it for information.

## 3. CONFLICT OF INTERESTS

Many companies employ scientists to carry out and publish research - whilst this does not necessarily invalidate research, it should be analysed with this in mind. Research can also be misrepresented for personal or financial gain.

## 4. CORRELATION & CAUSATION

Be wary of confusion of correlation & causation. Correlation between two variables doesn't automatically mean one causes the other. Global warming has increased since the 1800s, and pirate numbers decreased, but lack of pirates doesn't cause global warming.

## 5. SPECULATIVE LANGUAGE

Speculations from research are just that - speculation. Be on the look out for words such as 'may', 'could', 'might', and others, as it is unlikely the research provides hard evidence for any conclusions they precede.

## 6. SAMPLE SIZE TOO SMALL

In trials, the smaller a sample size, the lower the confidence in the results from that sample. Conclusions drawn should be considered with this in mind, though in some cases small samples are unavoidable. It may be cause for suspicion if a large sample was possible but avoided.

## 7. UNREPRESENTATIVE SAMPLES

In human trials, researchers will try to select individuals that are representative of a larger population. If the sample is different from the population as a whole, then the conclusions may well also be different.

## 8. NO CONTROL GROUP USED

In clinical trials, results from test subjects should be compared to a 'control group' not given the substance being tested. Groups should also be allocated randomly. In general experiments, a control test should be used where all variables are controlled.

## 9. NO BLIND TESTING USED

To prevent any bias, subjects should not know if they are in the test or the control group. In double-blind testing, even researchers don't know which group subjects are in until after testing. Note, blind testing isn't always feasible, or ethical.

## 10. 'CHERRY-PICKED' RESULTS

This involves selecting data from experiments which supports the conclusion of the research, whilst ignoring those that do not. If a research paper draws conclusions from a selection of its results, not all, it may be cherry-picking.

## 11. UNREPLICABLE RESULTS

Results should be replicable by independent research, and tested over a wide range of conditions (where possible) to ensure they are generalisable. Extraordinary claims require extraordinary evidence - that is, much more than one independent study!

## 12. JOURNALS & CITATIONS

Research published to major journals will have undergone a review process, but can still be flawed, so should still be evaluated with these points in mind. Similarly, large numbers of citations do not always indicate that research is highly regarded.

**Level 4 'Extreme Citizen Science'**

- Collaborative science – problem definition, data collection and analysis

**Level 3 'Participatory science'**

- Participation in problem definition and data collection

**Level 2 'Distributed Intelligence'**

- Citizens as basic interpreters
- Volunteered thinking

**Level 1 'Crowdsourcing'**

- Citizens as sensors
- Volunteered computing

**Figure 1.1** The relationship between community researchers' level of involvement and power and control

| LOW | MEDIUM | HIGH |
|---|---|---|

TYPE OF INVOLVEMENT

| Data collection | Identifying respondents | **Co-designing research tools** | **Involvement in data anlysis** | Dissemination and lobbying | Identifying research problem |
|---|---|---|---|---|---|

POWER AND CONTROL

| Low | Medium | High |
|---|---|---|

actions involved in community research projects can straddle one or all

# Stages of research
## (deductive/linear model)

1. Governance and oversight of evaluation, including commissioning and specifying the evaluation where applicable.

2. Identifying research problem, developing questions.

3. Designing research methodology, including theory & literature, research design, sampling, instruments, details of fieldwork, analysis, write up and dissemination plans.

4. Identifying respondents.

5. Co-designing research tools.

6. Data gathering/collection.

7. Data analysis.

8. Writing up and co-authorship.

9. Dissemination, lobbying, policy impact/implications.

10. Policy re-design.

# Stages by level of skill/challenge

*Lower*

6. Data gathering/collection.

4. Identifying respondents.

*Medium*

5. Co-designing research tools.

9. Dissemination, lobbying, policy impact/implications.

7. Data analysis.

10. Policy re-design.

*Higher*

1. Governance and oversight of evaluation.

2. Identifying research problem, developing questions.

3. Designing research methodology.

8. Writing up and co-authorship.

# #britainbreathing



- Citizen sensors –  research on triggers for seasonal allergies
- Over 600 people fed into the app design
- http://britainbreathing.org/

# STOCKPORT
## EMOTION MAP

*Artist* CHRISTIAN NOLD & *Designer* DANIELA BORASCHI    STOCKPORT – SEP, 2007

to Manchester ↑

### Legend

HIGHEST EMOTIONAL AROUSAL

LOWEST EMOTIONAL AROUSAL

PARTICIPANT'S DRAWING

FELT A BIT NERVOUS

PARTICIPANT'S ANNOTATION FROM AN EMOTION MAP WALK

PARTICIPANT'S GPS TRACK FROM AN EMOTION MAP WALK

RIVER TAME

RIVER MERSEY

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### THE STOCKPORT EMOTION MAP

Whilst conventional maps show static architecture and exclude humans, this art project presents a vision of Stockport that represents the emotions, opinions and desires of local people. Over a period of two months in summer 2007, about 200 people took part in six public mapping events. This map collects together and shows the results of the two activities: Drawing Provocations & Emotion Mapping.

### DRAWING PROVOCATIONS

People were asked to sketch their responses to a variety of serious and humorous provocations about their daily lives such as what really annoys them about Stockport, where they meet their friends, as well as who are the most important and dangerous people in town. Other provocations were focused on the town and its history, river and landmarks. As a result, people enthusiastically created a huge pile of drawings which were scanned and used to create this map. As far as possible, all the drawings were placed in their geographically correct position or where people mentioned them.

### EMOTION MAPPING

The second activity involved people walking freely through Stockport equipped with a special device invented by the artist, that measured their emotional arousal in relation to their g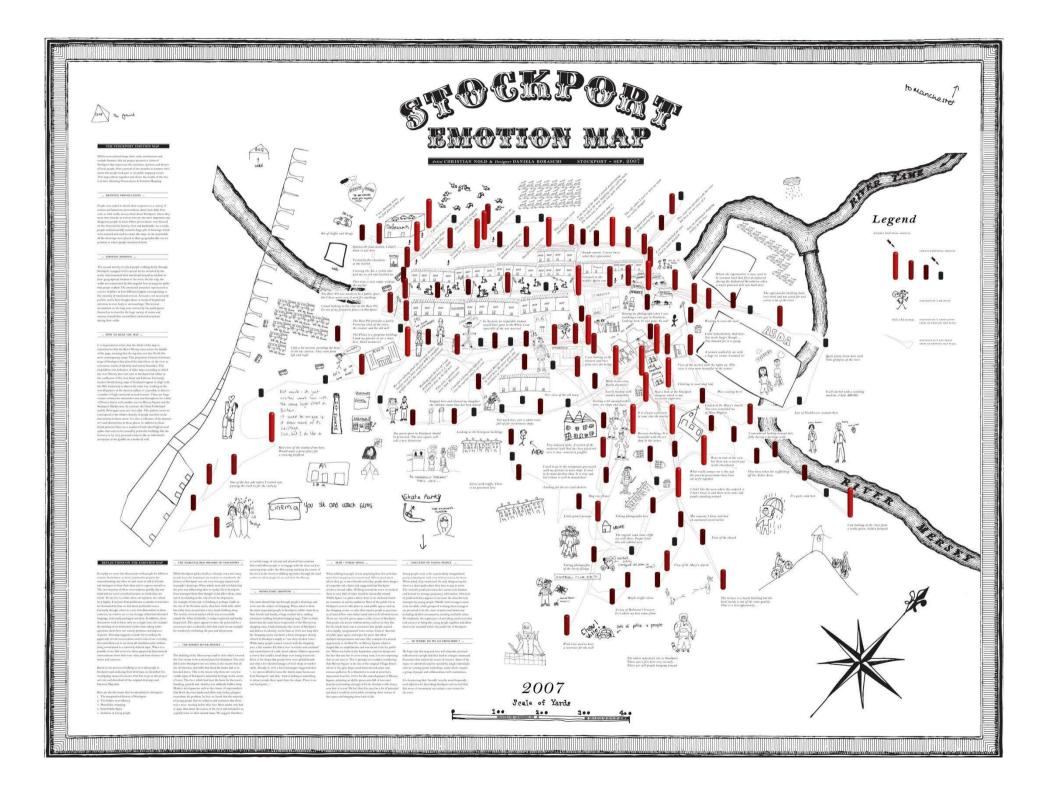eographical location in the town. On the map, the walks are represented by the angular lines tracing the paths that people walked. The emotional arousal is represented as a series of pillars at four different heights corresponding to the intensity of emotional arousal. Arousal is not necessarily positive and is best thought about in terms of heightened attention to ones body or surroundings. The textual annotations on the map were written by the participants themselves to describe the huge variety of events and sensory stimuli that caused their emotional reactions during their walks.

### HOW TO READ THE MAP

It is important to notice that the whole of the map is orientated so that the River Mersey runs across the middle of the page, meaning that the top does not face North like most contemporary maps. This projection is based on historic maps of Stockport that placed the main focus on the river as a resource, source of identity and county boundary. This map follows the definition of older maps according to which the river Mersey does not start in Stockport but rather at the confluence of the river Goyt and Etherow. Curiously, modern North facing maps of Stockport appear to align with the M60 motorway to almost the same way. Looking at the overall pattern of the emotion pillars, it is possible to discern a number of high emotional arousal clusters. There are large clusters around the old market area and throughout the whole of Princes Street with smaller ones in Mersey Square and the Stockport Market area. In contrast, the Great Underbank and St. Petersgate areas are very calm. This pattern seems to correspond to the relative density of people and thus social interactions in those areas. It is also a reflection of the amount of visual distractions in those places. In addition to these broad patterns there are a number of individual high arousal spikes that seem to be caused by particular buildings like the brewery or by very personal contexts like an individual's annoyance at the graffiti on a medieval wall.

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### REFLECTIONS ON THE EMOTION MAP

Everyday we enter into discussions with people for different reasons. Sometimes, we have a particular purpose for communicating, but often we just want to talk to friends and strangers to hear their ideas and to express ourselves. The vast majority of these conversations quickly slip our mind and are never recorded because we think they are trivial. Yet we live in a time when our opinions are valued very highly. Everyone from politicians to market researchers are fascinated by how we feel about particular issues. Curiously though, when we enter into discussions in those contexts, we tend to use a very strange stilted and alienated language, that neatly packages our ideas. In addition, these discussions tend to focus only on a single issue, for example the building of an incinerator rather than asking wider questions about how our society produces and disposes of goods. This map suggests a model for recording the apparently trivial conversations and events of our everyday lives and allows us to see them all simultaneously without being constrained to a narrowly defined topic. When it is possible to see this overview, these apparently disconnected conversations show their true value and form clusters of issues and concerns.

Based on the process of talking to over 200 people in Stockport and analysing their drawings, we identified five overlapping issues of concern. Feel free to go to the project web site and download all the original drawings and Emotion Map data.

Here are the five issues that we identified for Stockport:
1. The marginalised history of Stockport
2. The hidden river Mersey
3. Monolithic shopping
4. Semi-Public Space
5. Isolation of young people

### THE MARGINALISED HISTORY OF STOCKPORT

While Stockport prides itself as a historic town and many people view the looming train viaduct as a landmark, the history of Stockport was not very strongly represented in people's drawings. When asked, most did not think that the past was influencing their everyday life in Stockport. Even amongst those that thought it did affect them, some saw it as standing in the way of new developments. An example of this type of thinking is perhaps visible at the site of the Norman castle, then later cloth mill, which has today been turned into a very brash clothing shop. The nearby covered market which was successfully named the 'Glass Umbrella', is today neglected and hardly frequented. This space appears to have the potential for a conversion into a cultural centre that could set an example for sensitively combining the past and the present.

### THE HIDDEN RIVER MERSEY

The building of the Merseyway mall in 1965 which covered the river seems to be a pivotal point for Stockport. Not only did it series Stockport into two town, it also meant that all the old factories and mills that lined the banks had to be knocked down. This is the reason why there are very few visible signs of Stockport's industrial heritage in the centre of town. The river which had been the basis for the town's founding, growth and identity was suddenly hidden away. Modern developments such as the cluster of supermarkets that block the river banks and allow only stolen glimpses exacerbate the problem. In fact, we found that the majority of young people that we talked to did not know that there was a river running below their feet. Most adults only had a vague idea about the course of the river and included it as a gently trace on their mental maps. We suggest that there is a whole range of cultural and physical interventions that could allow people to re-engage with the river, such as canoeing trips under the Merseyway, marking the course of the river in the street or drilling spy-holes through the road surface to allow people to see and hear the Mersey.

### MONOLITHIC SHOPPING

The main thread that ran through people's drawings and texts was the subject of shopping. When asked to draw the most important people in Stockport, whilst some drew their friends and family, a large number drew smiling consumers holding branded shopping bags. There is little doubt that the main factor responsible in the Merseyway shopping area, which dominates the centre of Stockport and defines its identity. As far back as 1970, not long after the shopping centre was built, a local newspaper already referred to Stockport simply as "one shop window town". While many people seemed content with the shopping area, a fair number felt that it was "soveless and outdated" and wanted more of a café-street culture. Others expressed a worry that smaller local shops were being forced out. Most of the shops that people drew were global brands and only a few sketched images of local shops or market stalls. Already in 1974 a local newspaper suggested that "...we cannot afford to loose the family-name businesses from Stockport" and that, "what is lacking is something to attract people there apart from the shops. There is no real local point...".

### SEMI-PUBLIC SPACE

When talking to people it was surprising how few activities apart from shopping were mentioned. When asked about where they go to meet friends and relax, people drew images of corporate café chains and suggested that Stockport revolves around coffee. Walking around the town we noticed there is very little of what would be classically termed 'Public Space', i.e. places where there is no exclusion based on economic or social conditions. Most of the public life in Stockport seem to take place in semi-public spaces such as the shopping centre or cafes that require people to purchase or at least follow some behavioural rules to be allowed access. There are very few green spaces in the centre of Stockport that people can access without money and use as they like. On the whole there was a consensus that people wanted a less rigidly 'programmed' town centre. Current theories of public space agree and argue for areas that allow multiple interpretations and uses. One example of a missed opportunity is the Bear Pit on Mersey Square which is staged like an amphitheatre and was meant to be for public use. When one looks at the features of concrete design and the fact that one has to cross a busy road, it is not surprising that no one uses it. This is perhaps even sadder considering that Mersey Square is the site of the original Village Green where in the past, large social festivals took place and tensions pulled in. It is illustrative to look at an artist's impression from the 1970's for the redevelopment of Mersey Square, picturing an idyllic green area full of trees and benches contrasting strongly with the desolate traffic heavy area that it is now. We feel that this area has a lot of potential and that it would be worthwhile revisiting other visions of this space and bringing them back to life.

### ISOLATION OF YOUNG PEOPLE

Young people seem to be a particularly marginalised group in Stockport with very little provision for them. When asked, they mentioned the only thing set-up for them is a skate-park which they have to pay to enter. The council's youth provision also seems to be limited and focused on teenage pregnancy information. This lack of youth activities appears to increase the class division amongst the young people. Middle class teenagers seem to be invisible, while groups of working class teenagers are perceived to be the cause of anti-social behaviour including alcohol consumption, stealing and body crime. We emphasise the importance of providing youth activities and services to bring the young people together and allow them to be included within the public life of Stockport.

### SO WHERE DO WE GO FROM HERE?

We hope that this map and text will stimulate personal reflections for people and then lead to a larger communal discussion that reframes the issues of concern. Some of the topics we identified could be tackled by simple individuals such as running youth workshops, while others require a group of people and collaborations with institutions.

It is heartening that "locally" was the most frequently used adjective for describing Stockport and we feel that this sense of community can sustain a new vision for the town.

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## 2007
### Scale of Yards

100    200    300    400

# Participatory RCTs

- Large N field trials with partners: social housing organisation; local government bodies; national charities; local recycling & environmental organisation; local community groups
- Pros evidence, partners in research design e.g treatments, controls, target populations, measurement of outcomes etc, free specialist expertise, trialling innovations
- Cons: lack of/negative results e.g. social information, concerns about reputation/effectiveness, impacts on staff and volunteers, time, restrictions of the method e.g. young people

**WORLD ANTIBIOTIC AWARENESS WEEK**

16-22 November is WHO World Antibiotic Awareness Week, which aims to increase awareness of global antibiotic resistance to avoid further emergence and spread. Learn more.

# LONGITUDE PRIZE OPEN

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Longitude Prize is a challenge with a £10 million prize fund to help solve the problem of global antibiotic resistance. It is being run by Nesta and supported by Innovate UK as funding partner

Enter Now

# Quality frameworks

- Research conducted outside of academia
- Accreditation scheme for local politicians-evaluations of local government initiatives
- Basic standard for evaluation e.g. minimum of pre- and post- measures, observable measures where possible
- Submitted research designs for review and advice by mixed team (e.g. supervision)

# Quality frameworks

- 25 organisations initial discussion
- 18 full applications
- 1 unsuccessful; 2 withdrawn; 15 successful
- Excellent use of existing administrative data, and mixed methods

| Authority | Topic | Quantitative methods and measures | Qualitative methods | Documentary evidence |
|---|---|---|---|---|
| Flyde | E-democracy | – No. of online transactions overall<br>– Public consultation responses<br>– Customer feedback responses<br>– No. of councillors with published emails, websites, and blogs<br>– No. of hits on councillor websites and councillor-initiated online surveys<br>– Correspondence conducted electronically<br>– No. of new community websites | – Individual case studies<br>– In-depth interviews with councillors and community organizations<br>– Comments from online discussion on community forums | – Community websites and online discussion forums |
| Hyndburn | Housing market renewal/ regeneration | – No. of legal enforcement actions against landlords<br>– No. of neighbourhood visits by councillors<br>– Level of central government funding | – In-depth interviews with councillors, senior officers and front-line council staff<br>– Case studies of community groups and neighbourhood work | – Constituent correspondence<br>– Grounds given in legal cases<br>– Presentations by councillors<br>– Press reports<br>– Pre- and post-photographs<br>– Neighbourhood issues resolved |

# Qualitative analysis – coding frameworks

| Theme or point being made | | Lyrics from song |
|---|---|---|
| **Fire and Rain – Willie Nelson** | | |
| **Liz** | **Rachel** | |
| Isolated through divorce or bereavement<br><br>Loss of optimism and future plans<br><br>Pressures from outside cause problems<br><br>Wants to express emotion but lack of emotional support | Bereavement<br><br>Angry about their death/blaming others<br><br>Isolated | Just yesterday mornin', they let me know you were gone<br>Suzanne the plans they made put an end to you<br>I walked out this morning and I wrote down this song<br>I just can't remember who to send it to |
| Social isolation<br><br>Emotions up and down/mental health issues<br><br>Drawing on past for strength<br><br>Unwilling to face bereavement | Loss/dwelling on the past<br><br>Lonely | *Chorus*<br>I've seen fire and I've seen rain<br>I've seen sunny days that I thought would never end<br>I've seen lonely times when I could not find a friend<br>But I always thought that I'd see you again |

# Coding frameworks cont.

- Imagine your data is a set of pieces of clothing.

- Suggest 2 different ways to organise the clothes into piles

- What question did you ask to get to these categories?

# Statistical data review

- Haven't tried doing quantitative analysis
- But review of existing health data against direct experience
- High risk groups for alcohol harm
- Identified data gaps e.g. JSNA missing data on younger age groups

# Qualitative data collection



**SHARE A SECRET?**

You are invited to anonymously contribute a secret to a group art project. Your secret can be a regret, fear, betrayal, desire, confession or childhood humiliation. Reveal *anything* - as long as it is true and you have never shared it with anyone before.

Steps:
Take a postcard, or two.
Tell your secret anonymously.
Stamp and mail the postcard.

Tips:
Be brief – the fewer words used the better.
Be legible – use big, clear and bold lettering.
Be creative – let the postcard be your canvas.

**SEE A SECRET.**
www.postsecret.com

place postage here

PostSecret
13345 Copper Ridge Rd
Germantown, Maryland
20874

# Elite

Percentage of population

**6%**

Average age

**57**

## This is the wealthiest and most privileged group in the UK:

- They are the UK's biggest earners
- They score highest for social, cultural and economic factors
- Many went to private school and elite universities - 24% of people in this group were privately educated, far more than in any other class group
- This class is most likely to be found in London and the home counties
- This group is exclusive and very hard to join, most come from very privileged backgrounds
- 97% of people in this group own their own home

You | Elite | Established middle class | Technical middle class | New affluent workers | Traditional working class | Emergent service workers | Precariat

© BBC

# Conceptual/definitional work

- "Can the views of those unversed in the ways of academic discourse really be elucidated in such a way as to add anything to what is ultimately a philosophical and scientific issue?"
- Definitions of social exclusion (late 1990s) political philosophy and public/social policy disciplines
- Relative, participation in socially valued activities, multiple deprivation
- Parallel group to LSE academics – community equivalents!
- Started from direct experience, then moved up level of abstraction
- Led with core academic debates e.g. on what is a 'normal' activity

# Definitional work – results

- Agreed on core aspects of definition - participation in socially valued activities, emphasis on multiple deprivation and on relativity
- Challenges to definition (tough reviewers!):
  - Overly static – need to incorporate process/dynamic aspects
  - Overly individualistic or focused on individual people, neglects collective dimensions of exclusion e.g. places
  - Additional category of 'normal activities' - consumption of public services and public goods
  - Agreed that agency was important but did not accept implicit view that voluntary social exclusion e.g. gated communities was not a social policy problem
  - More emphasis on the need for intervention on social justice grounds