Public Trust in Scientific Research

Sharmila Nebhrajani OBE
Director of External Affairs
Why does public trust matter?

- All state funded research (and the priority it takes against other uses of public money) is funded with the “implicit consent” of the public. And of course we are the public;

- Pre-Brexit public trust in institutions, from the banks to the NHS, was falling. Post Brexit a putative “expert backlash”; we need to make sure research is not a victim of this trend;

- Public trust in charities also falling (fund-raising tactics, CEO salary concerns, Kids Company) yet maintaining charity investment in medical research (£1bn p.a.) is critical

- Public participation in clinical trials, cohort studies and sharing their data access for research may be vulnerable if the public lose faith in biomedical science.

- Public trust needs to come from the healthy (research as a public good) as well as the sick (research to make me better) – and is central to making the case for sustained investment in Science

Confidence that
- money invested in research is well spent,
- that the research process is fair and unbiased and
- that results are reliable;
Ipsos MORI Veracity Index 2015 (%)

<table>
<thead>
<tr>
<th>Role</th>
<th>Trust (%)</th>
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<tbody>
<tr>
<td>Doctors</td>
<td>89</td>
</tr>
<tr>
<td>Teachers</td>
<td>86</td>
</tr>
<tr>
<td>Judges</td>
<td>80</td>
</tr>
<tr>
<td>Scientists</td>
<td>79</td>
</tr>
<tr>
<td>Hairdressers</td>
<td>69</td>
</tr>
<tr>
<td>The Police</td>
<td>68</td>
</tr>
<tr>
<td>Man in the street</td>
<td>68</td>
</tr>
<tr>
<td>Clergy/priests</td>
<td>67</td>
</tr>
<tr>
<td>Television news readers</td>
<td>65</td>
</tr>
<tr>
<td>Civil Servants</td>
<td>59</td>
</tr>
<tr>
<td>Lawyers</td>
<td>51</td>
</tr>
<tr>
<td>Managers in the NHS</td>
<td>49</td>
</tr>
<tr>
<td>Charity chief executives</td>
<td>47</td>
</tr>
</tbody>
</table>

Published survey data (not academic data but useful nonetheless) indicate that scientists and doctors remain well trusted by the public.
Research is a team sport with huge potential benefits but it requires trust in the whole system ....

* Total annual funding including devolved nations’ funding, Innovate UK, EU funding, etc. likely to be in excess of £8bn.
Where is trust strongest (and weakest) in our system?

Has trust changed over time?

There have been changes across the three waves of the Wellcome Trust Monitor in the levels of trust the public place in the professions and institutions asked about (Figure 2.13).[

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Doctors, nurses and other medical practitioners</td>
<td>72%</td>
<td>67%</td>
<td>64%</td>
</tr>
<tr>
<td>Scientists working in universities</td>
<td>61%</td>
<td>66%</td>
<td>59%</td>
</tr>
<tr>
<td>Medical research charities</td>
<td>60%</td>
<td>60%</td>
<td>37%</td>
</tr>
<tr>
<td>Scientists working for pharmaceutical companies††</td>
<td>26%</td>
<td>-</td>
<td>32%</td>
</tr>
<tr>
<td>Scientists working in private industry††</td>
<td>-</td>
<td>32%</td>
<td>29%</td>
</tr>
<tr>
<td>Journalists</td>
<td>4%</td>
<td>8%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Unweighted base: 1,179, 1,396, 1,524
Weighted base: 1,179, 1,396, 1,524

With respect to doctors, nurses and other medical practitioners, almost three-quarters (72 per cent) of the public had complete trust, or a great deal of trust, in these individuals to provide accurate and reliable information about medical research in 2009. By 2012, this had fallen to 67 per cent, and in 2015 stands at 64 per cent, which while significantly below 2009 levels, does not represent a further significant decline since 2012.

Turning to scientists, the proportion of the public saying they have complete trust, or a great
Media coverage is becoming more sceptical....
Concentrating on three key issues.....

- **Collaboration with industry** - building public trust and understanding of why scientists work with industry

- **Reproducibility** - building public faith in the integrity of the research process and the value from research

- **Sharing Data** – building public’s confidence in how their data is used; the “social contract” for health
Collaboration with industry - building public trust and understanding of why scientists work with industry

### Why do we work with industry?

- **Science boosts economic growth**; MRC can support wealth as well as health
- **Access to more money** for research than public sector alone
- **Translation** of insights of research into new products, drugs, devices needs industry
- **Acceleration** of scientific advance by collaboration of academic and industry scientists
- Improved **research quality** (collaborative research is more highly cited than that of industry or academic alone)
- Industry collaborations can may help **interdisciplinary** research e.g. informatics, medical device development, animal health or human nutrition

### Our guiding principles

- **Tails and dogs** - Commercial activities in support of core MRC purpose and strategy
- **MRC priorities** - we retain the responsibility to prioritise our resources, both money and intramural researcher time
- **Independence** - Industry does not have undue influence on strategy, study design, conduct or sharing results
- **Non-exclusive** - MRC funding usually not exclusive to one company without contribution in kind from that company
- **Sharing outputs** - Results of research to be peer-reviewed and reported widely for subsequent research and teaching benefit
Reproducibility - building public faith in the integrity of the research process and the value from research

Reproducibility and the conduct of research

**Data dredging**
Also known as p-hacking, this involves repeatedly searching a dataset or trying alternative analyses until a 'significant' result is found.

**Omitting null results**
When scientists or journals decide not to publish studies unless results are statistically significant.

**Underpowered study**
Statistical power is the ability of an analysis to detect an effect, if the effect exists – an underpowered study is too small to reliably indicate whether or not an effect exists.

**Issues**

**Errors**
Technical errors may exist within a study, such as misidentified reagents or computational errors.

**Underspecified methods**
A study may be very robust, but its methods not shared with other scientists in enough detail, so others cannot precisely replicate it.

**Weak experimental design**
A study may have one or more methodological flaws that mean it is unlikely to produce reliable or valid results.

Joint work of MRC/BBSRC/AMS/WT – statement in October
Explaining and demonstrating high funder and researcher standards to tackle reproducibility issues

- Personal integrity
- Honesty
- Professionalism

- Policies and guidance – identify and manage conflicts of interest
- Improve peer review
- Greater emphasis on methodology in funding applications
- Support for statistics and experimental design
- Promote data sharing and open science
- Promote high-quality reporting
- Promote better education and training
- Good data management (including long term retention, archiving, sharing policies)
Managing (potential) conflicts of interest is becoming a public issue .......

Conflicts of interest, both real and perceived, pose a significant threat to the integrity, validity and trustworthiness of science.

**ABPI disclosure database** c50% of doctors and health care professionals refused to be named

**All Trials** Campaign continues – conflicts of interest ill dealt with and evidence base published is still flawed

**BMJ/NEJM on-going debate** on declaring industry funding and BMJ stance on industry co-funded studies (industry funding is a de-facto conflict of interest)

**BMJ calling for an independent review of statins** following *The Lancet* review claiming them to be safe and effective.

**NHS England is launching a major consultation** on proposals to strengthen the management of conflicts of interest.

**AMS conflicts of interest workshop**, exploring what constitutes a conflict of interest in academic/industry relationships and how interests should be managed and reported.

**NHS England propose requiring every hospital to publish register** of consultants earnings to unearth potential conflicts of interest.
Just at a time when we are going to re-engage with the public about the importance of sharing their health data for research ....

<table>
<thead>
<tr>
<th>Organisation</th>
<th>A great deal</th>
<th>A fair amount</th>
<th>Just a little</th>
<th>Heard of, know nothing about</th>
<th>Never heard of</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS</td>
<td>12%</td>
<td>21%</td>
<td>29%</td>
<td>21%</td>
<td>16%</td>
<td>1%</td>
</tr>
<tr>
<td>Commercial organisations</td>
<td>16%</td>
<td>58%</td>
<td>25%</td>
<td>27%</td>
<td>31%</td>
<td>1%</td>
</tr>
<tr>
<td>Academics researchers</td>
<td>18%</td>
<td>56%</td>
<td>25%</td>
<td>25%</td>
<td>31%</td>
<td>1%</td>
</tr>
</tbody>
</table>

*See report for full question wording

Source: Ipsos MORI/Welcome Trust

Base: 2017 GB adults, aged 16+
Data may also be the “canary in the mine” for wider scientific collaboration with industry....
We need to communicate simply but energetically to combat wariness.

Lots of initial uncertainty and wariness

<table>
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<th>Lack of understanding around current data-use and sharing</th>
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<tr>
<td>Most haven’t thought about private sector/academic/charities’ involvement in NHS</td>
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<tr>
<td>Individual-level data thought of as ‘my data’. Aggregate data as ‘statistics’ (instinctively more benign)</td>
</tr>
<tr>
<td>Little knowledge of safeguards and how datasets are handled</td>
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<tr>
<td>Most assume rules are in place</td>
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Future communication challenges
We need a (re)new(ed) social contract – grounded in public discussion and understanding – to reinforce trust in science......

Public question if commercial access is consistent with ‘promotion of health’

- Care Act 2014 – data can be shared for provision of care or promotion of health
- Scepticism towards commercial interest leading to socially beneficial outcomes
- Even the more pragmatic lack awareness of the role commercial interests play in health (e.g. provide essential services/drug trials)

New innovations mean new challenges

- Rise of wearables, passive data collection without full consent (e.g. small print Ts and Cs) links to questions of ownership and ethics
- Individuals unaware of potential autonomy to shape own care

Communications need to:

- Tackle scepticism and low awareness of commercial access
- Signal potential benefits and risks of data and tech innovations
We are all part of the building of the new social contract...

- **MRC-funded scientists** participating in engagement activities. Sharing our research work with the public who fund it and the wider world is a crucial part of the MRC mission.

- **The MRC festival** (an annual event) encourages MRC funded units, centres and institutes to showcase and discuss their work through events and activities around the UK and beyond.

- **Facilitate public conversation on sharing data** – Wellcome Independent Task Force on Data sharing, post Caldicott

- Reinforcement of **importance of industry collaboration** to scientific endeavour (joint approach with Genomics England, Academy of Medical Sciences, BSA, others?)
Thank you
Questions....?

(sharmila.nebhrajani@headoffice.mrc.ac.uk)