

Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines: next steps

Report of an implementation workshop held by the Academy of Medical Sciences on 5 July 2017

The Academy of Medical Sciences

The Academy of Medical Sciences is the independent body in the UK representing the diversity of medical science. Our mission is to promote medical science and its translation into benefits for society. The Academy's elected Fellows are the United Kingdom's leading medical scientists from hospitals, academia, industry and the public service. We work with them to promote excellence, influence policy to improve health and wealth, nurture the next generation of medical researchers, link academia, industry and the NHS, seize international opportunities and encourage dialogue about the medical sciences.

Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences, or its Fellows.

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Executive Summary

In June 2017 the Academy of Medical Sciences published the report, 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines'. In July 2017 the Academy held a workshop to explore the implementation of the report's recommendations. Discussions were facilitated along the report's three key themes: the generation, trustworthiness and communication of scientific evidence.

Improving the generation of scientific evidence

- To continue to build on the recent progress in patient and public involvement (PPI), delegates emphasised the need to produce guidance for targeted PPI that maximises the value of patient involvement.
- Coordinated improvement based on agreed standards in the training of researchers, healthcare professionals and the general public in statistical concepts and methodological designs is needed and should be embedded throughout the educational pathway.
- Bodies such as the Academy should continue to work with research institutions to emphasise the need for accuracy and quality in published results, which are recognised by the Research Excellence Framework (REF).
- Research using 'real world data' is an increasingly important source of evidence, which needs to be carefully considered by funders and regulators. The UK should seek to take the lead on data standards through NHS Digital and Health Data Research UK and should support increased use of 'real world data' with infrastructure to improve data access, linkage, and sharing.

Improving the trustworthiness of scientific evidence

- Dissemination and 'intelligent openness' of research should be actively encouraged with the development of incentives, such as a system linked to future funding or accreditation schemes, and rigorous monitoring of compliance.
- To encourage declarations of interest there should be clearer guidance and greater standardisation of the process. A central repository of interests that is accessible and easy to understand should be explored.
- There is a range of resources offering guidance on academia-industry relationships, and harmonisation of high quality guidance that looks beyond the biomedical sphere is needed. Communicating the need for industry involvement in research is the collective

responsibility of the research community. The community should demonstrate existing safeguards and champion best practice.

Improving the communication of scientific evidence

- The ongoing efforts to ensure that NHS Choices and patient information leaflets have accessible formats and relevant, contextualised information with a focus on patient-centred questions should be supported.
- A labelling system that clarifies to journalists and press officers the relevance of the evidence to healthcare should be developed by the Science Media Centre to improve media reporting of scientific research.
- Funders such as the MRC should consider creating codes of practice for media reporting for their grant awardees, and further guidance on best practice for press officers should be explored through collaborative meetings convened by Stempra.
- The use of joint decision-making to engage patients in their care with should be enhanced with additional regulated guidance to healthcare professionals and patients, led by NICE in collaboration with NHS Choices.

Overview

Recent high-profile media debates have queried whether the underpinning evidence for the use of licensed medicines is robust, relevant to the patient population, trustworthy, and communicated accurately in an accessible and usable way.

In June 2017 the Academy of Medical Sciences published a report on 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines', which made recommendations to strengthen the role of scientific evidence in decision-making about medicines.¹ The report explores how scientific evidence can be improved to strengthen its role in decisions made by patients, healthcare professionals and others.

On Wednesday 5 July 2017 the Academy of Medical Sciences held an implementation workshop for this report, which was chaired by Professor Sir John Tooke FMedSci. The meeting convened key stakeholders that are involved in the production and dissemination of scientific evidence from across the biomedical field. Together, delegates explored priorities for implementation of the Academy's recommendations and highlighted organisations that could take a lead on such implementation.

The workshop began with a short introductory presentation in which the Chair highlighted the report's mandate to put evidence at the heart of an individual's decision-making regarding medicines. While focused on medicines, many outputs from the report have implications across other disciplines. Delegates spent the majority of the workshop in discussion groups, assessing the report's recommendations around the themes of generation, trustworthiness and communication of scientific evidence. This meeting report provides a summary of the discussion across these groups. A full list of participants can be seen in Annex 1 and an agenda for the event is found in Annex 2.

The workshop discussions are informing the Academy's implementation plans for the report's recommendations, including actions by the Academy itself.

¹ Academy of Medical Sciences (2017) *Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines*. <https://acmedsci.ac.uk/file-download/44970096>

Generation of evidence

One group discussed recommendations in the Academy of Medical Sciences' report on 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines' which pertained to the generation of evidence.

Summary of the discussions

Recommendation 1: Involving patients, carers and the public in research

Full recommendation

Building on existing good practice, **funding bodies, universities, research institutions**, medical research charities and the **pharmaceutical industry** should increasingly seek to involve patients, carers and the public in the design, delivery and dissemination of research, and consider it a key part of how research excellence is characterised across the system as appropriate. Processes and practices for involving patients, carers and the public in research should be systematically evaluated to inform the evidence base and enhance future practice. Specifically, we recommend that:

- a. **Research funders**, including **medical research charities** and **industry**, require applicants to detail in their grant applications their plans for involving and engaging patients and the public in their research as a condition of funding. Funders should evaluate whether involvement and engagement initiatives have been carried out and request that these are described in the end-of-grant report or in other reporting systems such as Researchfish.
- b. **Universities, research institutions** and **industry** tackle the barriers to patient, carer and public involvement and engagement, paying particular attention to training and support for researchers and the public.
- c. **Research funders** from across the sector, including **medical research charities** and **industry**, come together to develop a mechanism of monitoring the development of relevant and appropriate activities for involving and engaging patients and the public in research. They should identify best practice and ensure it is disseminated to

researchers and the public. An initial meeting on this topic could be led by **INVOLVE**, part of the National Institute for Health Research (NIHR).

Delegates reported that there have been significant improvements in patient and public involvement (PPI) in research in recent years, led by charities and industry and supported by funders. Participants felt that this progress should be celebrated and better championed to encourage best practise and improve public opinion.

Some delegates raised their concern that the success of PPI has encouraged the emergence of professional patient representatives to the detriment of involving more 'lay' patients and carers. Care should be taken to ensure those with the most valuable experience from a broad base of patients and carers are given the opportunity to participate in PPI. In addition, managing potential conflicts of interest is vital to ensure independent PPI as, for example, a patient may be a trial participant or have a pre-existing role which could impact on their ability to provide an unbiased perspective. It was noted that many organisations are aware of these issues, with charities in particular alert because of reputational risks. The 'Working Together Guide' produced by Consumers Health Forum of Australia and Medicines Australia was cited as an example of a tool that can help ensure meaningful PPI with appropriate management of conflicts of interest.²

To continue to build on the recent progress in PPI, delegates particularly emphasised the need to produce guidance around when and how to most effectively involve patients in the research process. For example, in the context of a clinical trial, PPI is likely to be more valuable in ensuring appropriate clinical outcomes than determining randomisation criteria. The most appropriate uses of PPI may also vary between types of research. For example, patient-focused clinical work may be open to comprehensive PPI at all stages whilst more fundamental or pre-clinical research might benefit from more targeted patient input. Optimal PPI may also vary between sectors with, for instance, industry valuing the role of PPI in improving patient recruitment and provision of additional feedback on the investigational product. The group felt that any centralised approach to PPI should reflect these differences and ensure flexible guidance that can be tailored appropriately.

It was felt that protocols for high impact PPI would form an important piece of methodological research in itself. Delegates noted that INVOLVE is beginning to explore how co-production can be used to facilitate PPI in research. Clear definition of the PPI's purpose and associated protocols within a study would facilitate meaningful PPI that progresses the research agenda without hindering innovation.

² Consumers Health Forum of Australia & Medicines Australia (2015) *Working Together*.
<https://medicinesaustralia.com.au/wp-content/uploads/sites/52/2015/08/Working-Together-Brochure-2015.pdf>

Recommendation 2: Addressing gaps in training in research methods and statistics

Full recommendation

We recommend that those involved in the conduct of clinical research, including **universities**, **research institutions** and **industry**, should provide training in research methods and the use of statistics in evaluating the benefits and harms of medicines for staff across all career stages, from early career researchers to established researchers, as part of their continuing professional development (CPD). Similar courses should be provided for healthcare professionals by **universities** and **Medical Royal Colleges** as part of their training or CPD programmes. Existing courses should be reviewed and, where necessary, new courses established to accommodate the full range of evidence-generating approaches for assessing the benefits and harms of medicines. These should assess the relative value, strengths and limitations of different approaches, including new and emerging methods, and the questions they are best suited to address. These bodies should also instil an ethical research framework within which they expect staff to work, as outlined in the 'Universal ethical code for scientists', and promote high standards of research conduct.³ The Health Education England (HEE)/NIHR Masters in Clinical Research degree is an example of how training in research methods could be delivered for researchers.⁴

Whilst recognising that there are already many activities in this area, delegates felt that **Recommendation 2** was particularly important given the ongoing issues with research reproducibility.⁵ The importance of the limited proportion of healthcare professionals (HCPs) with a good understanding of research methods and statistics was also emphasised, illustrated for example by the widening gap between the number of consultants (who do not have much research training) and clinical academics.

It was recognised that the concept of team science⁶ is vital, as individuals cannot be expected to be highly skilled in every aspect of research methodology and statistics. However, a cultural shift to ensure a minimum understanding of core principles is needed. Delegates agreed that any further actions should focus on effectively progressing existing efforts, rather than duplicating work.

It was emphasised that training in statistical concepts and methodological designs must be embedded throughout the educational pathway. Creative, accessible, solutions are needed to increase the public's understanding of certain basic methodological concepts such as the

³ Government Office for Science (2007). *Rigour, respect, responsibility: A universal ethical code for scientists*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/283157/universal-ethical-code-scientists.pdf

⁴ <http://www.nihr.ac.uk/funding-and-support/funding-for-training-and-career-development/training-programmes/nihr-hee-ica-programme/nihr-hee-ica-programme-mres.htm>

⁵ Academy of Medical Sciences (2015). <https://acmedsci.ac.uk/file-download/38189-56531416e2949.pdf>

⁶ Academy of Medical Sciences (2016) *Improving recognition of team science contributions in biomedical research careers*. <https://acmedsci.ac.uk/file-download/38721-56defebabba91.pdf>

differences between randomised control trials and observational studies. The Schools Teaching Awareness of Randomised Trials (START) competition was given as an example of such a solution.⁷ To improve the understanding of researchers in more advanced concepts, delegates emphasised the need to improve training in PhD programmes. They suggested that funders could encourage this by incorporating the delivery of such training into funding applications. Finally, delegates noted that any training scheme to create a skilled healthcare workforce should include the full range of HCPs, including nurses, pharmacists, GPs, and others.

In the development of new training programmes, delegates suggested the Academy, the Academy of Medical Royal Colleges (AoMRC), Universities UK (UUK) or other relevant stakeholder should take a convening role to ensure harmonisation. As the report emphasises the importance of robust and appropriate research methodology, delegates also felt that the Academy should champion inclusion of experimental protocols within funding applications. Finally, delegates felt that the Academy should support learned societies and others to gather evidence on skills gaps to inform future policy decisions.

Recommendation 3: Enhancing the recognition of robust research findings

Full recommendation

We recommend that in the next Research Excellence Framework (REF) process, the **Higher Education Funding Council for England** (HEFCE, relevant functions expected to be assumed by Research England in the future) and its **counterparts in the devolved nations** should incorporate Lord Stern's recommendation for a new, institutional-level environment assessment. We propose that such environment assessments record measures taken to increase the robustness and reliability of research, including work to ensure adherence to ethical codes of research practice, data-sharing policies, and recognition and reward for efforts to enhance reproducibility.

Delegates commented that enhancing the robustness and reliability of research requires more than their recognition in the REF. They noted that the Academy's 'Reproducibility and reliability of biomedical research: improving research practice' report contains many recommendations to address the underlying issues.⁸ Some delegates noted that some good practice already exists which could be replicated in different research areas. In clinical trials, for instance, registration, protocol publication and submission of summary reports post-trial is increasingly becoming routine practice and this could be adopted by other study types.

To progress this work further, delegates felt that the Academy should continue to encourage best research practices and communicate the basic principles of evidence generation to enhance the understanding of their uses and importance. Universities could support this with clear and strong messaging on the need for accuracy and quality in published results, and moderated press releases. Delegates also felt the Academy could have a role in identifying possible improvements in training and appropriate incentives to increase the robustness of research.

⁷ <https://www.hrb-tmrn.ie/start-competition/>

⁸ Academy of Medical Sciences (2015) *Reproducibility and reliability of biomedical research: improving research practice*. <https://acmedsci.ac.uk/policy/policy-projects/reproducibility-and-reliability-of-biomedical-research>

Recommendation 4: Ensuring best use is made of new sources of evidence

Full recommendation

To complement current initiatives to improve data sharing and linkage, we recommend that:

- a. **Funding bodies** invest in research into understanding how to view and interpret the totality of outcomes from different study designs, including randomised controlled trials (RCTs), observational studies and novel approaches. We also recommend that they prioritise research into improving methodologies for analysing data from new sources of evidence, such as 'real world data', that take account of bias and confounding. This work should include investment in capacity building for skills in managing and analysing large data sets, as well as developing appropriate environments for greater data sharing and linkage, and quality-assured platforms for health research and real-time monitoring of outcomes. These platforms must provide appropriate safeguards to ensure data subjects' privacy and confidentiality.
- b. The **global research community** works together to develop internationally agreed data standards, best practice guidelines and robust methods for collecting, analysing and using 'real world evidence' to inform the use of medicines.

Research using 'real world data' is an increasingly important source of evidence, which needs to be carefully considered by funders and regulators. Delegates felt that terminology in this area should be better aligned, aided by conversation with patients, to strengthen the use of patient data in research alongside more traditional sources of scientific evidence. In addition, protocols, regulations and standards to combine 'real world data' with traditional sources of evidence should be explored further. The lack of internationally agreed standards was also identified as an obstacle, but delegates noted the opportunity for the UK to be a leader in this field. They suggested that Health Data Research UK⁹ could assemble a group to develop standards, robust methods and best practice guidelines for collecting, analysing and using 'real world data'.

Existing systems, such as the Medical Research Council (MRC)/NIHR Methodology Research Programme (MRP) and the Wellcome Trust, could be a source of funding for further research into the use of 'real world data'. However, it was noted that financial investment in methodologies for the use of routinely-collected health datasets will only pay dividends if data access systems also improve and better platforms for sharing and linking data are established. Delegates suggested NHS Digital was best placed to take forward this work.

⁹ <https://www.mrc.ac.uk/about/institutes-units-centres/uk-institute-for-health-and-biomedical-informatics-research/>

Next steps

A wide range of implementation actions were discussed. Specific outcomes from these discussions included the need for research to assess different approaches and critical stages where PPI's value is maximised (**Recommendation 1**). INVOLVE was identified as a key stakeholder in taking this forward, and it was suggested that it could convene a meeting to identify research topics, best ways to monitor PPI activities, and disseminate and implement best practice for PPI.

To address gaps in training for HCPs and researchers (**Recommendation 2**), it was suggested that a central coordinating body such as the Academy, AoMRC, UUK or others could look to provide central support in defining curriculum standards. UK Research and Innovation (UKRI) was tasked by participants with taking forward REF development in a manner that enhances research reproducibility and robustness (**Recommendation 3**). There were also calls for the Academy to take forward the implementation of recommendations in its 'Reproducibility and reliability of biomedical research: improving research practice' report.¹⁰

Funders could consider the prioritisation of research that supports the use of new sources of evidence such as 'real world data' (**Recommendation 4**). Use of 'real world data' is intrinsically linked to data access, and issues in this area remain challenging. In the development of internationally agreed standards for collecting and analysis these data, it was felt that the UK should strive to become a leader in the global research community, and delegates suggested that Health Data Research UK could form a high-level expert group to rapidly progress this agenda.

¹⁰ Academy of Medical Sciences (2015) *Reproducibility and reliability of biomedical research: improving research practice*. <https://acmedsci.ac.uk/policy/policy-projects/reproducibility-and-reliability-of-biomedical-research>

Trustworthiness of evidence

One group of delegates discussed the recommendations in the Academy of Medical Sciences' 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines' report which aim to further the trustworthiness of scientific evidence.

Summary of the discussions

Recommendation 5: Publication of research findings

Full recommendation

We support ongoing initiatives to enhance the dissemination of and access to research findings, including greater publication of rigorous results regardless of outcome, reporting of findings in more accessible formats, trial registration, and infrastructure funding for data archiving and curation. To complement these efforts, we recommend that:

- a. **Universities, research institutions** (led by Universities UK) and **industry** (led by the Association of the British Pharmaceutical Industry, ABPI, and the BioIndustry Association, BIA) support their staff in academia and industry in their efforts towards increased openness by providing appropriate incentives, rewards and recognition, and systems to enable this, such as those outlined in the Academy's report, 'Improving recognition of team science contributions in biomedical research careers'.¹¹ These organisations should recognise clear and accurate communication of research findings as an explicit criterion for career progression, promotion and reward.
- b. The **Higher Education Funding Council for England** (HEFCE, relevant functions expected to be assumed by Research England in the future) and its **counterparts in the devolved nations** galvanise change by requiring that institutional 'intelligent openness' initiatives are reflected in REF environment statements in the next REF process, in addition to the reproducibility efforts described in **Recommendation 3**.

¹¹ Academy of Medical Sciences (2016) *Improving recognition of team science contributions in biomedical research careers*. <https://acmedsci.ac.uk/file-download/38721-56defebabba91.pdf>

c. **Those who fund research**, including **industry**, incentivise the communication of results for the projects that they support by requiring in applications an effective plan for the communication and 'intelligent openness' of results. Researchers would need to demonstrate that they had adhered to these as a condition of future funding.

It was highlighted that there was already significant work being undertaken in this area, for example with the 'Concordat on open research data',¹² the 'Concordat to support research integrity',¹³ and requests for publication policies in many grant applications from funders such as the Wellcome Trust.¹⁴ However, it was acknowledged that lack of publication remains a significant problem. Some delegates felt a major impact of non-publication is significant duplication in research. As a first step to assessing this issue, an audit of the non-publication rate of phase I/II studies was suggested. Some delegates felt the UK's departure from the EU may provide opportunities for improving the issue, for example with possible changes in publication requirements of the Clinical Trials Regulation.

Overall, it was felt that better alignment, utilisation and policing of existing publishing incentives and requirements is needed. Those funding and evaluating research were thought to be key stakeholders in implementing this, with roles for medical research charities and regulatory bodies. Universities UK (UUK), UK Research and Innovation (UKRI) and ethics committees were suggested as key 'enforcers', with the withholding of future funding and ethics approval a powerful tool for policing publication. The Health Research Authority (HRA) was also noted as increasingly engaged in this area. However, delegates did not reach consensus on the practicalities of this policing, particularly regarding timescales as grant applications will often be submitted before research on existing grants has concluded. In addition, it was felt by some that embedding publication into funding requirements alone would not satisfy some of the greater ambitions of open data.

The Academy defines 'intelligent openness' as disclosure of information in a manner that is accessible, assessable and usable by the intended audience, while respecting privacy and reasonable commercial concerns.¹⁵ Some participants felt that improvements in 'intelligent openness' in industry have not been seen to the same extent within academia, and that greater acknowledgment of this is needed by bodies such as the Academy. The Athena SWAN Charter, which has helped to encourage and recognise good practice in promoting equality in higher education, was suggested as an effective model that could be applied to 'intelligent openness' initiatives to drive institutional change on transparency and open access.

¹² Research Councils UK (2016) *Concordat on Open Research Data*.

<http://www.rcuk.ac.uk/documents/documents/concordatonopenresearchdata-pdf/>

¹³ Universities UK (2012) *Concordat to support research integrity*. <http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/the-concordat-to-support-research-integrity.pdf>

¹⁴ <http://wellcomeopenresearch.org/>

¹⁵ Academy of Medical Sciences (2017) *Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines*. <https://acmedsci.ac.uk/file-download/44970096>

Recommendation 6: Developing frameworks for declaring and managing interests

Full recommendation

To facilitate greater declaration and management of interests, we recommend that:

- a. **Research Councils and Universities UK** (for academic research), **trade bodies** (for commercial research), and the **media regulators** (including the Independent Press Standards Organisation, IPSO, and the Independent Monitor for the Press, IMPRESS) develop frameworks for declaring and managing financial and non-financial, direct and indirect interests that fit the needs of staff in their sectors. Where these are already in place, they should be reviewed in light of the principles we outline in **Online annex F**.¹⁶ These frameworks should provide a protective environment, where interests can freely be declared and discussed to ensure that appropriate safeguards can be put in place should a competing or conflict of interest be identified.
- b. The **International Committee of Medical Journal Editors'** (ICMJE) declaration of interests is adopted as a standard format for declaring interests across the sector.¹⁷ In the spirit of 'intelligent openness', organisations should use this standardised declaration to establish publicly accessible registers of interests (for example on organisational websites).

It was acknowledged that there is a difference between declaring interests and managing interests, and the group discussion primarily focused on the declaration of interest. Delegates suggested standards that identify key research stages at which interests must be declared should be developed. Some delegates felt greater clarity is needed on the public's expectations of commercial research in fulfilling this recommendation as industry is likely to consistently have financial interests that could be interpreted as conflicting. It was also highlighted that interests are not limited to financial interests, and this should be reflected in any new framework.

New guidance from NHS England on managing conflicts of interest in the NHS¹⁸ has recently come into force, along with existing frameworks from the ABPI¹⁹ and others. Many participants agreed that such multiple frameworks are difficult for researchers to navigate and alignment between frameworks should therefore be sought and highlighted. Open Researcher and Contributor ID (ORCID), which provides an online registry for researchers, was suggested as one possible central repository that could hold declarations of interests for researchers.²⁰ Some delegates felt that the Academy, learned societies and others should show leadership to facilitate a centralised and publicly accessible resource for an individual's declaration of

¹⁶ <http://www.acmedsci.ac.uk/evidence/annexes/F>

¹⁷ <http://icmje.org/conflicts-of-interest/>

¹⁸ NHS England (2017) Managing conflicts of interest NHS. <https://www.england.nhs.uk/wp-content/uploads/2017/02/guidance-managing-conflicts-of-interest-nhs.pdf>

¹⁹ <http://www.abpi.org.uk/our-work/disclosure/Pages/DocumentLibrary.aspx>

²⁰ <https://orcid.org/>

interests, and should encourage their Fellows/members to lead by example in using such as resource.

Recommendation 7: Developing best practice guidelines for academia–industry relationships

Full recommendation

Informed by, but not reliant on, the development of the frameworks described in **Recommendation 6**, we recommend that **funding bodies, academia** (led by Universities UK) and industry (led by the ABPI and the BIA) work together to develop clear guidelines that define best practice in terms of the relationship between academia and industry and the management of competing interests that might arise. In developing these guidelines, these organisations should consider how the following key principles are implemented when evidence related to the use of medicines is developed in academic clinical trials funded by a commercial partner (full details in **Online annex F²¹**):

- **Research funding:** All funding from commercial partners should be disclosed and governed by the institution's policies for such funding, which should be informed by the best practice guidelines we recommend are developed. Academic researchers should be aware that other personal payments such as consultancy fees, and payments for speaking at meetings or sitting on advisory panels could raise potential concerns that their research is biased and untrustworthy. There should be greater openness about how the research funding is distributed within the institution (e.g. the NHS Trust or research department).
- **Study design:** Academic and commercial partners should work together to design studies in a way that minimises biases as far as practically possible. All protocols should be made publicly available on completion of the research to allow for independent analysis of the design and methods, and researchers should be transparent in publications about how the study was designed. Consideration should be given as to whether study designs could benefit from public or patient involvement and external peer-review.
- **Trial registration:** All clinical trials should be registered on a recognised, open and searchable trials register with a summary of the trial protocol, before the first participant is recruited. We strongly

²¹ <http://www.acmedsci.ac.uk/evidence/annexes/E>

²² The Research Ethics Service (now part of the Health Research Authority) defines a DMC as 'a group of people that reviews accumulating data in a clinical trial and advises the sponsor (directly or indirectly) on the future management of the trial. It mainly reviews safety and efficacy data but may also see quality and compliance data. The DMC is usually privy to interim comparisons by arm and sees data in a format that is not normally widely shared beyond the core statistical team.' National Research Ethics Service, National Patient Safety Agency (2010). *Data monitoring committees in clinical trials: Guidance for research ethics committees*. <http://www.hra.nhs.uk/documents/2013/10/data-monitoring-committees-in-clinical-trials.pdf>

encourage the registration of observational epidemiological studies that explore the effects of treatments.

- **Contracts:** All contracts between academia and industry should be made publicly available (with personal and commercially sensitive information redacted) and should provide clarity on specific items, including data access and holding, details of funding and to whom it is paid, and conditions for data analysis and publication. All contracts should also include a requirement to disclose competing interests.
- **Data holding and access:** Data should be managed responsibly, in a way that protects confidentiality for justifiable commercial, privacy, safety and security reasons. Contracts should clearly specify who holds the data, what the data can be used for, who they can be used by and with whose agreement, and who can access the data and by what means, providing justification for any limits to data access.
- **Data analysis:** Academic and commercial partners should work together to ensure that data analysis is conducted in a way that minimises biases as far as is practically possible. They should also be transparent about the analytical process in their publications. Data analysis should be undertaken by statisticians independently from the study teams, monitored by an independent Data Monitoring Committee (DMC) and auditable.²²
- **Publication of findings:** in full regardless of the outcome. A summary of results should be made publicly available on the database where the trial is registered within one year of completion of the trial, or within the timelines agreed if a deferral has been granted. Where applicable, the full Clinical Study Report, or its equivalent in non-commercial settings, should also be made publicly available. Where appropriate consent has been provided, de-identified individual patient-level data should be made available to researchers on request, with a commitment that no reasonable request would be refused.

Participants raised the concern that public trust in research tends to decrease the more industry is involved. This issue is not localised to medical research, but is seen across a wide range of research areas. As such, organisations including the UKRI, ABPI, and the National Academies should work collaboratively to better publicise the existing safeguards for industry involvement and the need for continued industry involvement in research.

Sense about Science have a project aimed at clarifying and publicising contracts between academia and industry. Employers have a role in mandating declarations of interests and encouraging best practice through employee contracts. However, contracts are reflective of individual organisations' policies and some participants felt a trusted organisation should have a role in the alignment of these individual policies.

Delegates emphasised the need to harmonise existing guidelines for academia–industry relationships where possible. The Academy, Royal Society and Royal Academy of Engineering were suggested as potentially leading this process – with an opportunity to have common guidelines across disciplines. Engagement with the World Health Organization, who have

produced standards for both industry and international non-governmental organisations on reporting clinical trial results, was also suggested.²³

To maximise the publication of data, delegates suggested that consent forms could be adapted to allow patients to require non-identifiable data to be shared. The Academy was identified by several participants as being well placed to provide a leadership role in this area, and could convene further work. Participants highlighted the need for the end users of research, including patients the National Institute for Health and Care Excellence (NICE), NHS England and the Medicines and Healthcare products Regulatory Agency (MHRA), to also be involved in this process.

Next steps

It was felt that many aspects of these recommendations have broader implications outside of medicine, and should therefore be taken forward by multidisciplinary umbrella bodies such as UKRI. Delegates suggested that to improve dissemination and 'intelligent openness' of research (**Recommendation 5**) more incentives and rigorous 'policing' is needed. The championing of funders whose grants are contingent upon publication was suggested, along with alignment to open access initiatives and the development of an accreditation scheme for publication standards. The Academy and others could show leadership in this area, but it was suggested that UKRI could explore the development of a science-wide 'Athena SWAN-style' model for accreditation. It was also noted that the REF could be used to further this issue, and UUK could investigate incorporation of publication practices into university rankings.

Delegates called for further work to provide clear guidelines determining the research stage at which different interests should be declared (**Recommendation 6**). Reliance on many disparate databases of declaration of interests could be reduced by the development of a central repository for this information, but there was debate as to who would be best placed to own and manage such a repository. UUK was identified as a leading stakeholder, with ORCID linking to researcher profiles. The Academy could convene relevant groups to improve harmonisation between disparate systems.

Participants noted the continuing negative public perception of industry, despite the sector leading the research community in many aspects of 'intelligent openness' (**Recommendation 7**). Delegates emphasised that it is a collective responsibility of all sectors to advertise the safeguards in place for industry involvement in academic research. All best practice guidelines should be based on a robust and transparent system and guidelines that are applicable beyond medicine would be particularly valuable. In this capacity, academies or learned societies would be valuable conveners of relevant groups, and UKRI was suggested to take actions forward. There was also a role identified for the Academy and membership bodies to lead by example and encourage greater data sharing.

²³ World Health Organisation (2017) Joint statement on public disclosure of results from clinical trials. http://www.who.int/ictrp/results/ICTRP_JointStatement_2017.pdf?ua=1

Communication of evidence

A third group focused on discussing recommendations to improve the communication of scientific evidence in the 'Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines' report.

Summary of the discussions

Recommendation 8: Improving the content of patient information leaflets

Full recommendation

We recommend that the **European Commission** and the **European Medicines Agency (EMA)** work with the **national regulatory authorities in EU Member States, pharmaceutical companies and patients, carers and the public** to improve the comprehension and readability of patient information leaflets in line with the current legislation. We recommend that such work is prioritised and ensures that a balanced appraisal of the medicine's potential benefits and risks is made accessible in these documents. In doing so, they should draw on the experiences of initiatives to enhance the accessibility of information about the potential benefits and harms, such as the Drug Facts Box initiative in the United States (US). We applaud the efforts of the Medicines and Healthcare products Regulatory Agency (MHRA) to date to improve the content and accessibility of patient information leaflets and encourage the regulator to continue its work in this area.

Delegates noted the importance of this recommendation, and emphasised the need for alignment with ongoing activity in this sphere. In 2014, a report was published with recommendations to the European Commission regarding improvements to patient information leaflets (PILs).²⁴ A follow-up report was released by the European Commission in March 2017 to take these recommendations forward.²⁵ The MHRA is collaborating with the European Commission and the EMA in this context. Delegates felt this activity has led to improvement in the readability of PILs but must be continued to ensure key information is highlighted in a relevant, accessible, and useful manner.

²⁴ Van Dijk L., et al. (2014) *Study on the Package Leaflets and the Summaries of Product Characteristics of Medicinal Products for Human use*.

http://ec.europa.eu/health/sites/health/files/files/committee/75meeting/pil_s.pdf

²⁵ European Commission (2017) *Report from the commission to the European parliament and the council*.
http://ec.europa.eu/health/sites/health/files/files/documents/2017_03_report_smpc-pl_en.pdf

PILs are highly regulated by the European Directive 2001/83/EC.²⁶ Current legislation requires the inclusion of side effects, numerical details of prevalence, and details of the medicine's uses but not the likelihood of benefits or the risks if a medicine is not taken. Delegates felt that this has contributed to historical resistance to inclusion of such information, as has concern in some Member States that such information may be seen as marketing activity by industry. However, delegates agreed that inclusion of information such as likelihood of benefits would contextualise the risk to the patient.

Some delegates felt that updating PILs for over-the-counter medicines should be a particular priority, as this remains an underdeveloped opportunity for discussion of the benefits and harms of important medicines. It was suggested that other sources of information could be developed in addition to PILs, and dispensers such as pharmacists were identified as an under-utilised resource for patient information. Pharmacists could receive communication training and help promote patient use of PILs.

Some delegates cautioned that the purpose of PILs must be clearly defined to allow inclusion of only essential legal information and the most pertinent patient information. These would avoid dilution of key messages and ensure PILs function as a useful and contemporary source of information. Patient involvement will be key to ensuring an optimal balance of information, and PILs should be developed with patient-centred questions at their centre to empower good choices around medicines. Delegates noted that in addition to changes to the content of PILs, changes to the format to have key patient information at the top for maximum visibility could significantly improve accessibility.

Finally, it was also noted that while PILs provide information once a medicine has been dispensed, it is also important for patients to receive information before they decide to agree to take a medicine.

²⁶ Directive 2001/83/EC of the European Parliament and of the Council of 6 November 2001 on the Community Code Relating to Medicinal Products for Human Use [2001] OJ L311.
http://www.ema.europa.eu/docs/en_GB/document_library/Regulatory_and_procedural_guideline/2009/10/WC50004481.pdf

Recommendation 9: NHS Choices as a central repository of information on the benefits and harms of medicines

Full recommendation

To enhance the availability and accessibility of contemporary information on medicines, we recommend that **NHS Choices** and its **equivalents in the devolved nations** develop clear information on the benefits and harms of medicines, and act as a central repository for use by patients and healthcare professionals. This online source of information should make direct reference to the underlying evidence; be updated as further evidence emerges; and detail relevant, robust and evidence-based decision aids that can be used by patients and healthcare professionals. In developing material, NHS Choices and its equivalents should continue to work with patient groups and medical research charities, increasingly consulting pharmaceutical companies as they move towards providing information on new drugs, and should coordinate with the MHRA to increase the availability, accessibility and reliability of information about the benefits and harms of medicines. NHS Choices and its equivalents, and the valuable information provided by **medical research charities**, should meet NHS England's Information Standard and the Plain English Campaign's Crystal Mark.^{27,28}

Delegates agreed that NHS Choices was a highly valuable resource and attributed part of this value to its holistic approach, which includes information on the condition as well as treatment options, and a rigorous clinical approval process for its information. Despite the competition from other online resources, NHS Choices is a prominent player in this space and its impact could be increased even further with social media usage to direct patients to this important source of information.

It was noted that NHS Choices is already working on updating its website to provide information on the benefits and harms of medicines. This was understood to be at beta test stage at the time of the workshop.

Delegates felt that NHS Choices should be seen as a trusted source of evidence, accessible to those who would otherwise rely on the knowledge of friends and family. NHS Choices could provide more information on lifestyle changes and complementary medicines, and link to robust information provided by medical research charities and other sources. Delegates noted the importance of including only high quality information from third parties. Accreditation via the Information Standard (which provides a 'quality mark' where it assesses an organisation to be a reliable source of health and social care information) was proposed.²⁹ However, some argued that poor awareness of this standard in the patient community could limit the impact of such accreditation. Delegates agreed that NHS Choices should continue its current process of evidence assessment with robust evidence review, adaptation to make it linguistically accessible, and clinical review, whilst maintaining short, accessible and clear formatting.

²⁷ <https://www.england.nhs.uk/tis/>

²⁸ <http://www.plainenglish.co.uk/services/crystal-mark.html>

²⁹ <http://www.nhs.uk/aboutNHSChoices/aboutnhschoices/Aboutus/Pages/the-information-standard.aspx>

Delegates felt that NHS Choices should continue to seek alignment and partnerships with other organisations and welcomed the collaboration between MHRA and NHS Digital to ensure NHS Choices and PILs are aligned. Participants did suggest that improved linkage to the British National Formulary (BNF)³⁰ would provide in depth information about medicines when needed, and that NHS Choices would benefit from better coordination with National Institute for Health and Care Excellence (NICE).

Recommendation 10: Improving the reporting of scientific evidence in the media

Full recommendation

To complement current initiatives to improve the reporting of scientific evidence in the media, we recommend that:

- a. The **Science Media Centre** works to develop criteria for and implement a 'traffic light' system for press releases of medical research that grade both the relevance of the research to clinical application and the robustness of the study. We also recommend that the **Science Media Centre** develops a series of workshops for news editors, sub-editors and non-specialist journalists to enhance their understanding and reporting of the scientific process.
- b. **Stempra** develops a code of practice for press officers to encourage best practice. Organisations that become a signatory to these principles could be authorised to use a hallmark to provide a clear signal that best practice guidelines for accuracy are promoted within the organisation, thereby increasing the credibility of the press release.
- c. **Funders** develop a code of practice for their grant awardees around how to describe the science that they fund in the media. This approach received support from the Chief Executive of the Medical Research Council (MRC). We therefore recommend that MRC leads on coordinating the development of this code of practice with the other major UK funders.
- d. **Universities** and **research institutions** play a greater role in ensuring that the research they host is portrayed accurately in the media. The **Higher Education Funding Council for England** (HEFCE, relevant functions expected to be assumed by Research England in the future) and its **counterparts in the devolved nations** should incentivise them to do so by requiring that the robustness of the approaches they adopted forms part of the institutional environment statement submitted to the REF, in addition to the reproducibility and 'intelligent openness' efforts described in **Recommendations 3** and **5** respectively.

³⁰ A pharmaceutical reference book published twice a year, which contains a wide spectrum advice on prescribing and pharmacology, along with specific facts and details, about all medicines that are generally prescribed in the UK.

Participants noted that the UK has world-leading health, science and environment specialist journalists, and felt that this resource could be better utilised for the communication of evidence. Some felt there is a need to better communicate to the public the concept of science as a process of testing over time, with the reporting of new research a part of this ongoing process. Furthermore, greater translation of evidence into the context of a clear narrative would increase both the accessibility of the information and the interest of the public.

There was agreement that a labelling system for press releases to contextualise the evidence would be a highly valuable tool for journalists and press officers. Peer review, stage of research including proximity to clinical improvement, and statistical strength such as association and causation were all noted as relevant elements to consider for evidence reporting in the media. Any labelling system should be accompanied by user guidance. However, the appropriateness of the specific development of a traffic light system as recommended in the Academy's report was debated as some felt that it may be difficult to implement and may lack sufficient detail and clarity.

Press releases have been attributed as the source of media exaggeration despite the fact that exaggerations in press releases have little correlation with likelihood of publication.³¹ Participants felt that the scientific community needs to encourage researchers and press officers to take responsibility for the quality of press releases and avoid exaggerated claims. It was highlighted that events such as the MRC's 'Conference for university press officers'³² indicate a culture change in which the community as a whole is seeking to be as accurate as possible but there was concern that funding pressures may prevent these changes being reflected in research institutions. Press officers and researchers, supported by their institution and funders, must therefore work together to ensure the accuracy of press releases. It was highlighted that the Stempra 'Guide to being a press officer'³³ covers many aspects of best practice for press officers and could be better used.

Finally, delegates debated if independent moderation was needed to ensure appropriate use and reporting of evidence in the media. It was emphasised that a positive and collaborative approach between scientists, press officers and journalists would be the most effective way to raise the standards of media coverage as a whole. Many delegates felt that press officers and journalists should be empowered to self-regulate, and balance institutional pressures alongside the responsibility to be measured and accurate. However, the option of media regulators exploring tougher interventions to ensure this progress was also discussed.

³¹ Sumner P., et al. (2014) *The association between exaggeration in health related science news and academic press releases: retrospective observational study*. BMJ 349, g7015.

³² <https://www.mrc.ac.uk/about/events/conference-for-university-press-officers/>

³³ Stempra (2009) *The Stempra guide to being a press officer*. http://stempra.org.uk/wp-content/uploads/2014/10/stempra_guide_to_being_a_press_officer.pdf

Recommendation 11: Supporting joint decision-making between healthcare professionals and patients

Full recommendation

To support joint decision-making between healthcare professionals and patients, we recommend that:

- a. **General practices** ensure that enough time is available through care planning and that adequate resourcing is provided by commissioners of primary care services to address patients' priorities and concerns regarding medication decisions. As proposed in **Recommendation 9**, the evidence provided by NHS Choices should assist in informing patients alongside their discussions with healthcare professionals.
- b. The **National Institute for Health and Care Excellence (NICE)**, in discussion with NHS Choices (or its equivalents in the devolved nations), coordinates the development of decision aids based on robust evidence, the source of which is open to scrutiny. These aids should be used to inform the decision-making process, helping patients and healthcare professionals decide on the most suitable course of action, including optimising treatment strategies and supporting the discussion of non-drug alternatives, such as lifestyle changes. The effectiveness of different forms of decision aids, including the use of machine learning and artificial intelligence, and their relative utility, should be subject to research evaluation and supported by funders, including the **National Institute for Health Research (NIHR)**.

It was noted that this recommendation aligns with ongoing work at NICE to explore new ways of including evidence in patient guidance and standards that will increase the accessibility of evidence and give information about alternative options. Participants discussed the importance of early conversations between healthcare professionals (HCPs) and patients about treatment preferences, priorities, goals, risks and benefits, and the need for ongoing dialogue throughout treatment. It was noted that this work overlaps with that previously discussed around **Recommendation 9** and NHS Choices, and the importance of close collaboration between these organisations was emphasised.

Delegates discussed the need for regulation of advice and information around joint decision-making, with much currently originating from charities. Some suggested that select charities could be assigned a 'lead' role in regulation of this information, with other charities applying to its information standards. Caution was noted in placing additional burden upon charities, and participants felt that any activity in this area should be undertaken in a highly collaborative manner.

Some delegates felt that the term 'joint decision-making' is not well understood by patients, and that there remains uncertainty in how to best undertake this process in an efficient and effective manner. It was noted that NICE hosts a 'Shared decision making collaborative', which is currently developing a guideline on joint decision-making to summarise the current

knowledge of best practice.³⁴ The importance of including artificial intelligence (AI) and machine learning in joint decision-making protocols was highlighted by some delegates.

Recommendation 12: Continuing dialogue and engagement with patients and the public

Full recommendation

To ensure the health system remains responsive to evolving public attitudes towards health, the use of medicines and the role played by scientific evidence in decisions about their use, we recommend that:

- a. **Health-related organisations** continue their dialogue and engagement with the public to ensure that they are responsive to evolving public attitudes and patient needs, and that they are engaging communities in enhancing the use of evidence as part of the decision-making process.
- b. **The Wellcome Trust** incorporates questions into its regular survey of public attitudes to science to monitor the impact of the recommendations made in this report on the use of evidence within the healthcare sector and in decision-making.³⁵

Participants agreed that continued dialogue and engagement with the public was critical. They also agreed that the Wellcome Trust's Monitor survey would be best placed to monitor the impact of this, and other, recommendations on the use of scientific evidence in decisions regarding medicines.³⁶

Next steps

The MHRA and industry leaders were identified as key stakeholders in updating PILs to include key information and likelihood of benefits (**Recommendation 8**). MHRA is already working with the EMA and it was felt that these changes could be done within the next two-four years. Delegates encouraged and supported the ongoing efforts by NHS Choices to provide clear information on the benefits and harms of medicines with reference to underlying evidence (**Recommendation 9**), although they suggested further linkage to BNF to provide more detailed information for clinicians. Moving forward, they also emphasised the need to maintain public trust and engagement as the NHS Choices brand evolves further.

Delegates encouraged the Science Media Centre to develop a labelling system for press releases and agreed that the MRC, in collaboration with other funders, could develop a code of practice for media reporting for grant awardees (**Recommendation 10**). Participants suggested further promotion of Stempra's 'Guide to being a press officer'³⁷ and suggested the

³⁴ <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

³⁵ <http://wellcome.ac.uk/what-we-do/our-work/public-views-medical-research/>

³⁶ <https://wellcome.ac.uk/what-we-do/our-work/public-views-medical-research#why-we-run-monitor>

³⁷ Stempra (2009) *The Stempra guide to being a press officer*. http://stempra.org.uk/wp-content/uploads/2014/10/stempra_guide_to_being_a_press_officer.pdf

Academy supports Stempra to convene a meeting of press officers and other relevant stakeholders to discuss a potential code of practice for press officers. It was emphasised that whilst regulatory systems such as Research Excellence Framework (REF) can be utilised, improving reporting of evidence was a collective responsibility of scientists, press officers, funders and journalists.

Delegates supported ongoing work at NICE to promote joint decision-making (**Recommendation 11**) but stressed the need for further engagement of NHS Choices. Participants also recognised the difficulties in undertaking joint decision-making considering the current pressures facing the NHS, which are not limited to consultation times. Delegates agreed that the Wellcome Trust survey could have a role in monitoring society to assess changes in the use of scientific evidence in decisions about medicines. Finally, delegates stressed the reward of restoring public trust in science and scientific evidence (**Recommendation 12**) and suggested that further promotion of independent organisations that check the accuracy of statistics (such as Fullfact³⁸) could play an important role in this.

³⁸ <https://fullfact.org/>

Conclusions

This meeting successfully brought together different participants with wide ranging views, and the resulting vibrant discussions represented the breadth and depth of participant's knowledge. The participants agreed that there is a need for further progress in the generation, trustworthiness and communication of scientific evidence and praised the emphasis throughout the report recommendations to progress existing initiatives and avoid duplication. While focused on medicines, the recommendations were deemed to have important international implications outside of medical science, and delegates championed a collaborative, collegiate, approach to their implementation. The discussions detailed in this meeting report are informing implementation by the Academy and others moving forward.

Annex 1

Attendees List

Chair

Professor Sir John Tooke FMedSci, Chair of the report Oversight Group, Academy of Medical Sciences

Breakout Group 1: Generation of scientific evidence

Professor Deborah Ashby OBE FMedSci, Professor of Medical Statistics and Clinical Trials; Co-Director of Clinical Trials Unit, Imperial College London

Professor Dame Sue Bailey DBE, Chair, Academy of Medical Royal Colleges

Professor Peter Brocklehurst FMedSci, Chair of the Methodology Research Programme Panel, Medical Research Council

Dr Andrew Clempson, Senior Research Policy Manager, Association of Medical Research Charities

Professor Sir Rory Collins FRS FMedSci, British Heart Foundation Professor of Medicine and Epidemiology; Head of the Nuffield Department of Population Health, University of Oxford

Professor Harry Hemingway, Professor of Clinical Epidemiology, University College London; Director, Farr Institute London

Dr Anthony Johnson, Vice President, Early Clinical Development, AstraZeneca

Professor Max Parmar, Professor of Medical Statistics and Epidemiology; Director of the MRC Clinical Trials Unit and the Institute of Clinical Trials and Methodology, University College London

Jo Revill, Chief Executive, British Society for Immunology

Sir Jim Smith FRS FMedSci, Director of Science, Wellcome Trust

Derek Stewart OBE, Associate Director for Patient & Public Involvement and Engagement, National Institute for Health Research

Breakout Group 2: Trustworthiness of scientific evidence

Dr Virginia Acha, Executive Director – Research Medical, & Innovation, Association of the British Pharmaceutical Industry

Jonathan Brüün, Chief Executive Officer, British Pharmacological Society

Sir Iain Chalmers FMedSci, Co-ordinator, James Lind Initiative

Dr Kevin Cox, Board Member, BioIndustry Association; Chief Executive Officer, Imanova UK

Rebecca Endean, Director of Strategy, UK Research and Innovation

John de Pury, Assistant Director of Policy, Universities UK

Dr Robert Frost, Head, R&D Policy & Scientific Affairs, GSK

Dr Fiona Godlee, Editor-in-Chief, BMJ

Dr Claire Hastings, Chair, Stempra

Dr Karen Kennedy, Director, National Cancer Research Institute

Dr Tony Peatfield, Director of Corporate Affairs, Medical Research Council

Professor Sir Nilesh Samani FMedSci, Medical Director, British Heart Foundation

Charlotte Urwin, Head of Standards, Independent Press Standards Organisation

Breakout Group 3: Communication of scientific evidence

Louise Cleaver, Product Lead for Medicines Information, NHS Digital

Simon Denegri, National Director for Public Participation and Engagement in Research, National Institute for Health Research; Chair, INVOLVE

Fiona Fox OBE, Chief Executive, Science Media Centre

Jonathan Heawood, Chief Executive Officer, IMPRESS

Professor Tim Higenbottam, Vice President, Faculty of Pharmaceutical Medicine

Dr Ian Hudson, Chief Executive, Medicines and Healthcare products Regulatory Agency

Professor Gillian Leng CBE, Deputy Chief Executive and Director of Health and Social Care, National Institute for Health and Care Excellence

Dr Imran Rafi, Chair of the Clinical Innovation and Research Centre, Royal College of General Practitioners

Suzie Shepherd, Council Member, Royal College of Physicians

Dr Louise Wood, Director of Science, Research and Evidence, National Institute for Health Research

Staff

Naomi Clarke, Communications Officer, Academy of Medical Sciences

Joe Clift, Interim Policy Manager, Academy of Medical Sciences

Dr Claire Cope, Policy Manager, Academy of Medical Sciences

Dr Katharine Fox, Policy Officer, Academy of Medical Sciences

Luiz Guidi, Policy Intern, Academy of Medical Sciences

Dr Helen Munn, Executive Director, Academy of Medical Sciences

Dr Rachel Quinn, Director of Policy, Academy of Medical Sciences

Dr Naho Yamazaki, Head of Policy, Academy of Medical Sciences

Annex 2

Date and location

Wednesday 5 July 2017, 09.00 – 13.00

Academy of Medical Sciences, 41 Portland Place, London, W1B 1QH

Agenda

Arrival	
09.00	Registration, teas and coffees
Welcome	
09.30	Chair's introduction: overview of the project and recommendations Professor Sir John Tooke FMedSci
09.50	Comments and questions from the room
Breakout sessions: identifying priorities for implementation	
<i>Teas and coffees available throughout</i>	
10.00	<p>Developing next steps In groups, identify the priorities for implementation of the report's recommendations and identify who should take the lead on taking these forward.</p> <p>Group 1: Generation of scientific evidence (Chapter 2) Facilitator: Professor Deborah Ashby OBE FMedSci Location: Council Chamber</p> <p>With a particular focus on: Involving patients, carers and the public in research [Recommendation 1] Addressing gaps in training in research methods and statistics [Recommendation 2] Enhancing the recognition of robust research findings [Recommendation 3] Ensuring best use is made of new sources of evidence [Recommendation 4]</p> <p>Group 2: Trustworthiness of scientific evidence (Chapter 3) Facilitator: Professor Sir Nilesh Samani FMedSci Location: Council Reception</p> <p>With a particular focus on: Publication of research findings [Recommendation 5] Developing frameworks for declaring and managing interests [Recommendation 6] Developing best practice guidelines for academia–industry relationships [Recommendation 7]</p> <p>Group 3: Communication of scientific evidence (Chapter 4) Facilitator: Mr Simon Denegri Location: Fellows' Room</p> <p>With a particular focus on: Improving the content of patient information leaflets [Recommendation 8] NHS Choices as a central repository of information on the benefits and harms of medicines [Recommendation 9] Improving the reporting of scientific evidence in the media [Recommendation 10] Supporting joint decision-making between healthcare professionals and patients, and</p>

	continued public dialogue and engagement [Recommendations 11-12]
Feedback	
11.30	Feedback Summary and discussion of each group's conclusions
12.20	Closing remarks Professor Sir John Tooke FMedSci
12.30	Lunch



Academy of Medical Sciences
41 Portland Place
London, W1B 1QH
+44(0)20 3141 3200

info@acmedsci.ac.uk
www.acmedsci.ac.uk

 [@acmedsci](https://twitter.com/acmedsci)

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