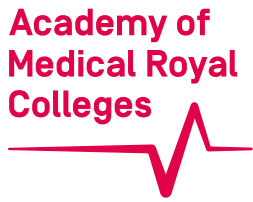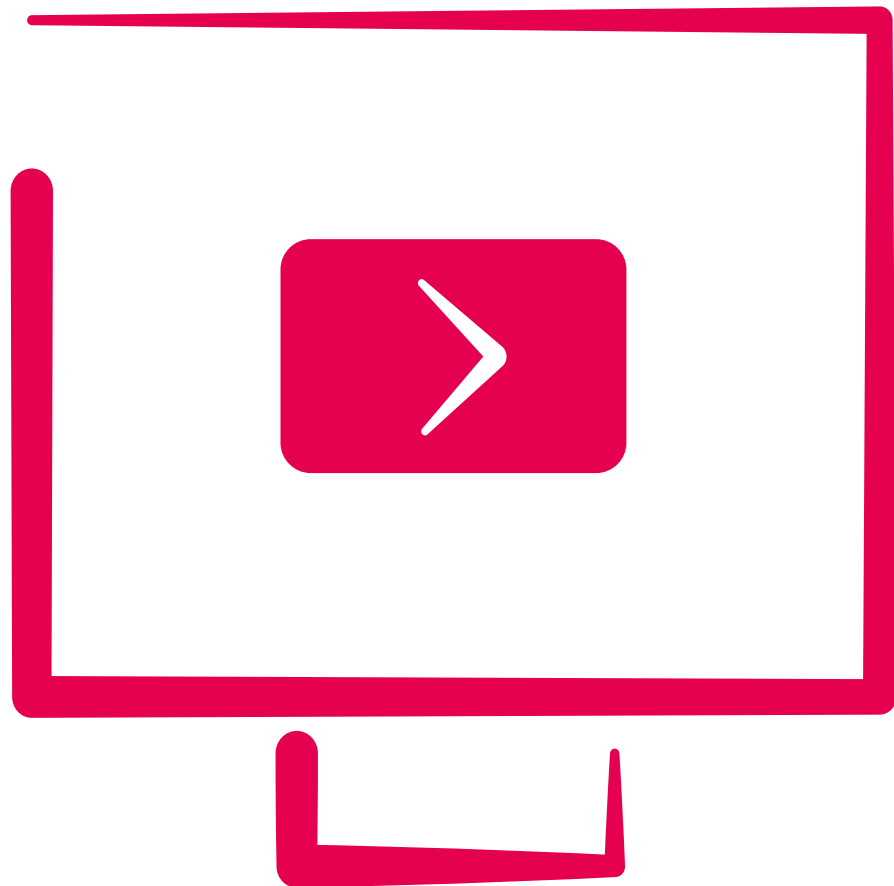May 2023

Academy of Medical Royal Colleges

Assuring the credibility of health information sources on social media platforms

These proposals are endorsed by:

The Academy of Medical Royal Colleges
The Academy of Medical Royal Colleges' Patient Lay Committee
NHS Providers
Patient Information Forum
Royal Pharmaceutical Society

Introduction

Social media content is a major and valuable source of health information for millions of people. It is vitally important that any information and advice which could impact on an individual's health and healthcare is accurate. Therefore, providing the public with some form of assurance on the quality and provenance of that health information is an important task.

It is unrealistic and not necessarily even desirable to seek to monitor every piece of health information on social media. However, we believe it is possible to devise a system to provide the public with guidance as to the credibility of the sources and providers of health information.

Background

Towards the end of 2021 the Academy of Medical Royal Colleges [the Academy] was invited by YouTube to provide an independent commentary on the paper from an expert panel convened the US National Academy of Medicine [NAM], which looked at whether the quality of health information on social media platforms [SMPs] could be assured in the context of the USA health landscape. YouTube was particularly interested from the perspective of information on YouTube which it owns, but the principles were generic.

As a result, in May 2022 the Academy published a paper on the principles and attributes of ensuring the credibility of health information in social media in a UK context. At the same time NHS England [NHSE], which had also been in discussions with YouTube, produced a standard for creating health content for NHS organisations.

YouTube also launched a new feature of health source information panels displayed on videos which have been verified as coming from an authoritative source. Currently only health organisations with government accreditation are eligible to have their videos verified. Organisations will have to self-certify against the NHS standard for creating health content in order to have a health information panel displayed on the content.

Since then in the US, a collaboration of the Council of Medical Specialty Societies, the National Academy of Medicine, and the World Health Organization has produced a further paper which expands on the original expert panel convened by NAM paper and seeks to identify how the principles set out in the original paper could be applied to not for profit and for profit organisations and for individuals. The WHO also produced its Let's flatten the infodemic curve paper in 2022 which provides some tips to the public for telling the

difference between reliable and unreliable information and stopping the spread of misinformation. The advice complements the principles and process set out in this document.

In further discussions between the Academy, NHS England [NHSE] and YouTube it was agreed that it would be useful to develop a set of principles and a subsequent process for assuring health information produced by both non-NHS accredited organisations (e.g. third sector, professional and academic bodies and commercial organisations) and by individuals. Any process/principles would be based on the NHS standard for creating content and relevant material from the US or elsewhere.

In early 2023 the Academy convened an Advisory Group to produce a set of processes and principles to inform this report. These form the content of this report. The Organisations involved then formally considered and endorsed the report. Additional organisations may choose to do so subsequently.

The report will be made available to YouTube and potentially, other SMPs providers. There will need to be discussions with SMPs and others as to who would be responsible for the assurance process and the precise details of how it might be implemented.

The result should be agreed principles and processes by which the credibility of providers of health information, and by proxy the quality of that information, on SMPs produced by both organisations and individuals could be assured.

Scope, definitions and caveats

What do we mean by social media?

The principles outlined in this document should apply to the production of any health information. Although this work initially started from discussions with YouTube relating to YouTube, the Academy has consistently been clear that we are not specifically producing a process just for YouTube. We believe these principles should apply to all online or digital health information and hope they would be adopted by the full range of SMPs.

What do we mean by health information?

In many cases what constitutes health information is self-evident i.e. clinical information or advice relating to the diagnosis, treatment and management of illness, disease or injury or wider epidemiological information. However, health information also covers issues of fitness, diet and lifestyle. This area has not been the focus of our work, but we would hope that providers of information on these topics would see the benefit of seeking the recognition and endorsement this process offers. We therefore see no reason these principles and process should not be applied to wider health and lifestyle information.

Application

Online health information is produced by a range of organisations (statutory, third sector, professional, academic) but also increasingly by individuals, often with a clinical background, (or indeed student clinicians) wishing to provide health information or act as 'influencers'.

Content providers who are registered healthcare professionals should be expected to confirm their registration. Those who are student health professionals but have not yet gained their professional registration should be explicit about their status and level of qualification.

We believe that the principles and requirements for accuracy, objectivity, impartiality and transparency should apply equally to whoever is producing health information for the public. It may be that slightly different processes are required for individual content providers than for organisations but, in principle, we would expect similar standards to apply.

In terms of organisations, NHS bodies in England are expected to follow the NHSE standard for creating health content and these principles and processes are intended to align with the standard. In addition the Patient Information Forum (PIF) has developed its PIF Tick for trusted information creators which provides a UK quality mark for healthcare information. Again these criteria have been aligned with the PIF Tick requirements and we would expect that any organisation meeting the thorough requirements of the PIF Tick could easily and perhaps automatically meet these requirements.

Assuring providers not content

This process cannot assure the accuracy and quality of every piece of health information. That is an impossible task. What we can seek to do is *assure the credibility of the sources/ providers of that information*. We recognise that is a proxy and will not assure the standard of every individual piece of information. However, confirming the credibility of the providers should provide the public with a degree of assurance. Crucially, it should be possible to implement such a scheme where assuring all individual content is not.

Obtaining buy-in

This is not a system of mandatory regulation of online information. That is not achievable and there will be different views as to whether it is even desirable.

The success of any processes will depend on both providers of content and SMPs themselves believing there is value in the exercise and wishing to participate and, of course, the public having awareness of and trust in the scheme.

Our principles and process do not seek to ban or censor any health information although we believe that SMPs should have robust processes for removal of false, harmful or hateful information. Rather we are seeking to provide a "certification" of assurance for the public i.e. if a source/provider is approved the public can be confident it comes from a credible source and has been produced to agreed standards and should therefore be accurate.

We would expect that having this verification should provide a major boost to the positioning of any provider via the SMP's algorithms. This quality assurance of providers should be a major factor in positioning above simple numerical popularity. Consequently, content providers would see the value of seeking this accreditation as the right thing to do both in terms of quality assurance and public benefit and for direct business benefit.

This does mean, however, that the principles and any process for assurance have to be proportionate and not burdensome to information providers or social media platforms. It will only be effective with their cooperation and buy-in.

Principles and compliance

The task

The task for the Advisory Group was:

— To identify the principles by which the credibility of both organisational and individual health providers should be evaluated

— To identify how compliance with those principles could be assessed for organisations and individuals both initially and on an on-going basis.

Principles

We believe that all health information should be:

— Evidence-Based. Sources should provide information that is consistent with the best evidence available at the time and meet standards for the creation, review, and presentation of content and relevant to context i.e. that is referenced, up to date, relevant and has trustworthy evidence sources. Evidence-based includes but is not restricted to formal scientific evidence but should meet recognised and transparent evidence standards

— Produced using consistent and documented processes. Sources should be able to provide evidence that they produce information through clear and consistent processes

— Transparent and accountable. Sources should be transparent about potential or perceived conflicts of interest including funding and advertising that might compromise or be perceived to compromise the quality of the information they provide

— Accessible. Content providers should be committed to producing information which is accessible and is designed to meet the needs of the intended audience.

Process for ensuring compliance

This is the key issue, and we recognise it is complex to get right. Any process cannot be so bureaucratic, complex or expensive that it deters providers from participating. However, if it is to be of value in providing assurance on the credibility of providers it has to be sufficiently robust. That requires a thorough initial process and arrangements for managing clear breaches of the process.

We believe there are three elements of an assurance process:

— **Initial assurance.** A "Registration" process which provides initial assurance as to the credibility of the source whether an individual or organisation

— **On-going assurance.** Regular reconfirmation that agreed principles and processes continue to be followed

— **Dealing with compliance failures.** A recognised process for managing real or perceived breaches of the process and principles.

Initial assurance/registration

This should entail:

— A self-assessment declaration on the process used by the provider to create the information showing how the four principles have been met

— For declared registered healthcare professionals, confirmation of their registration status. Student healthcare professionals who may not yet be fully registered should be explicit about their status and qualifications

— Checks by the SMP provider that previous postings have met their existing content and behaviour standards

A proposed self-assessment form is set out in the Appendix. The form has been designed to be usable by both organisations and individual content providers. The requirements set out in the form are directly based on and reflect the content of the NHSE standard for creating health content and the PIF Tick.

An organisation or individual that successfully completes the registration would receive accreditation as a credible provider of healthcare information. It is hoped that this would be perceived by the public as an indicator of quality, by content providers as valuable in its own right and by SMPs as a key driver for prominence and promotion on the platform.

While the registration process should incorporate the SMP confirming that the provider's previous content has met its existing content standards, the view of the Advisory Group is this registration process can only be prospective from an identified date. It is not possible or reasonable to apply registration requirements retrospectively to a previous back catalogue of work.

Precisely how this could be managed is to be determined. However, resources will be required for an organisation to manage the process and an online system created for applications.

On-going assurance

Some form of continuing assurance is essential to maintain the integrity of the system. Potentially that could be highly resource intensive. We therefore believe that regular reaffirmation of original registration (i.e. re-registration) is the most straightforward and pragmatic approach rather than a separate inspection/checking process.

The re-registration would require providers to confirm that they are still meeting the registration requirements.

The regularity of re-registration would need to be considered but should not be less frequent than every three years.

When a process for registration and on-going assurance is properly established consideration should be given to the feasibility some form of spot-checking.

Managing non-compliance

The third strand of assurance is having a process for taking action when there is a clear breach of processes. Again, this is potentially resource intensive but if it is perceived that there are never any consequences for flouting the principles or processes, there is little value in an assurance regime.

Clearly the range of sanctions in what is a voluntary process are limited. However, the prime expectation must be the removal of registration/accreditation where there is a sufficiently serious breach.

We would also hope that deliberate breaches of the requirements signed up to in the registration declaration would be a concern to system regulators for organisations or professional regulators for registered professionals.

If a registered health professional wilfully ignores undertakings they have signed up to, we believe that this is a matter of professional integrity and conduct. As such it should be a concern for the professional regulator and one on which they may need to take action.

The GMC, for example, expects that in any written, spoken or digital communication with the public medical professionals should:

— Be honest and trustworthy

— Make clear the limits of your knowledge

— Make reasonable checks to make sure any information you give is not misleading

— Declare any conflicts of interest

— Maintain patient confidentiality.

Wilful breaches of our principles would suggest a failure to meet these GMC standards and may warrant action by the regulator.

Similarly, we would hope that relevant system regulators (e.g. the Care Quality Commission and the Charity Commission) might wish to take action where an organisation is shown to blatantly ignore commitments they have signed up to regarding producing information.

There would need to be clear criteria and processes for managing complaints, including vexatious complaints, and investigating non-compliance with clarity on the decision-making process for removing registration, appeals etc.

We would hope that the instances requiring compliance action would be few — particularly as this is a voluntary scheme of certification. We would presume that those not minded to comply in the first place would not seek to apply. However, as stated before, there does have to be a process for ensuring compliance.

There may, of course, be inadvertent errors found in health information. That requires a process for correcting and updating information. The Patient Information Forum (PIF) provides support and training for content providers to assist them in producing high quality health information.

Managing non-compliance would logically sit with whoever is responsible for the registration process. Whoever has this responsibility will need to develop effective processes for managing complaints and non-compliance.

Implementation

A fundamental issue is who would undertake any registration and compliance process and how it would be resourced.

There would seem to be two options. Either:

— Individual SMPs agree to adopt the principles and process set out here and run the accreditation, registration and compliance process themselves

or

— The process of accreditation, registration and compliance is run independently of SMPs either by a stand-alone body or by another organisation.

There are arguments for and against both options. A system run by and funded by SMPs themselves would be simpler to establish. It is in many ways the correct place for this to be done, with SMPs themselves taking responsibility for material on their platforms. There could, however, be concerns about independence and consistency of application by SMPs.

Management of the process by a separate organisation does provide transparent independence. However, it may lack traction and it will require initial investment to establish and on-going funding to run such a system. In the longer term, it may be possible to charge registrants a fee, but financial modelling would clearly be required.

The Advisory Group is not equipped to determine this issue, but has made some general points:

— Close involvement and support of SMP providers is essential even if the process were managed separately. They will have a role in the registration process

— The process should not and need not be hugely complex or resource intensive, but it will require adequate funding to establish and then run registration arrangements.

— The process should be online and automated but that will require the development of suitable software to manage the process. That will necessitate initial capital investment

— We strongly believe that is important to run a small pilot exercise with a number of providers to check the useability of the process and to amend it in the light of agreed suggestions

— On an on-going basis, revenue and running costs will be needed to cover staffing to manage the work. That requirement may grow according to how much the initiative takes off.

Next steps

This report was agreed the Advisory Group which comprised representatives from the organisations listed below. It will now be presented to YouTube which initiated the work and then to other SMPs so that discussions can be held on ways to implement the findings.

Advisory Group membership

The Academy of Medical Royal Colleges
The Academy of Medical Royal Colleges' Patient Lay Committee
General Medical Council (GMC)
Medical Schools Council
National Voices
NHS England
NHS Providers
Patient Information Forum
Richmond Group
Royal Pharmaceutical Society
Royal College of Nursing
Two individual content creators

The report has been formally endorsed by:

— The Academy of Medical Royal Colleges

— The Academy of Medical Royal Colleges' Patient Lay Committee

— NHS Providers

— Patient Information Forum

— Royal Pharmaceutical Society

The GMC supports assuring the credibility of health information on social media platforms and the proposals set out in the report.

Appendix
Self-Assessment Declaration

This declaration is based on the requirements in the NHSE standard for creating health content and the PIF Tick.

The intention is that organisations wishing to seek accreditation by a particular social media platform would need to complete the declaration and show they are meeting the criteria.

1. Information is evidence-based

Content providers should offer information that is consistent with the best evidence available at the time and meet standards for the creation, review, and presentation of content i.e. that is referenced, up to date, relevant and has trustworthy evidence sources.

All organisational and individual content providers are expected to:

— Acknowledge the limitations and evolution of knowledge and that the risks and benefits are communicated in an accurate, balanced, unbiased way

— Clearly label information with the date it was last updated and strive to reassess and update content

— Demonstrate subject-specific expertise (i.e. consistent and well-regarded contributions in a given field)

— Synthesise information from multiple sources, rather than a single source and link to other credible sources

— Provide citations for information shared and evidence to justify claims

— Use peer review or another form of content review to vet information before sharing

— Signpost to relevant information within the resource e.g. further reading, other organisations' websites, local services, etc.

Please confirm that in producing your material you/your organisation meets **ALL** the above criteria.
YES/NO

If any of the criteria are not met please explain here:

2. Information is created using a consistent and documented process

All organisational and individual content providers are expected to have:

— A designated person accountable for the overall quality of health and care information production

— A defined process for producing health and care information that is kept under regular review

— A process for reviewing and updating health and care information within appropriate timeframes

— For organisations only: A sign off process which has been followed to ensure the final resource has adhered to quality control/assurance procedures.

Please confirm in producing your material that you/your organisation meets **ALL** the above criteria?
YES/NO

If any of the criteria are not met, please explain here:

3. Transparent and accountable

It is important that sources are transparent about potential or perceived conflicts of interest including funding and advertising and are committed to producing information which is accessible.

All organisational or individual content providers are expected to:

— Disclose, in a way accessible to content users, financial and non-financial conflicts of interest

— Disclose, in a way accessible to content users, relevant policy positions and lobbying activities

— Meet legal requirements in relation to confidentiality of patient data

— Provide a mechanism for public feedback and post public corrections or retractions.

Please confirm in producing your material that you/your organisation meets **ALL** the above criteria?
YES/NO

If any of the criteria are not met, please explain here:

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4. Accessible

It is important that sources are committed to producing information which is accessible and designed to meet the needs of the intended audience.

All organisational or individual content providers are expected to prioritise accessibility and equitable access to information by:

— Ensuring that material is written and presented to meet health and digital literacy standards

— Meeting the language and accessibility needs of the target audience.

Please confirm in producing your material that you/your organisation meets the above criteria. YES/NO

If any of the criteria are not met, please explain here:

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