Standardised Data on Initiatives (STARDIT)

Sharing the 'who', 'how' and 'what'

Public consultation report

September to December 2019

SCIENCE FOR ALL

WIKIMEDIA
MOVEMENT AFFILIATES

About this document

This document describes how the public were invited to be involved in giving feedback on the 'Standardised Data on Initiatives (STARDIT): Alpha Version'(1) between September 24th 2019 to the end of 2019. The feedback is then summarised into learning points and actions. These actions will be used to inform the co-creation of the Beta version of STARDIT, which will then be submitted for peer review. This report is licensed under a Creative Commons Attribution-ShareAlike 4.0 International Licence. This report has been written by Jack Nunn, Director of Science for All and PhD researcher at La Trobe University. This project is being run in partnership with the Wikipedia Journals (Wikimedia Foundation). More information can be found at ScienceForAll.World/STARDIT

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Public consultation

The 'Standardised Data on Initiatives (STARDIT): Alpha Version'(1) was published in September 2019. Opportunities to be involved in co-creating this version were advertised online using social media and shared via email to potential authors. Comments from co-authors were then incorporated into a series of versions, with all co-authors reviewing the final pre-print version.

The pre-print was shared online and promoted using emails, newsletter and social media. Feedback from the public gathered by:

- Emails
- Phone and video calls
- Online discussion forums
- Online forms
- Public events in London and Melbourne
- Face-to-face conversations

More information about the public event in London is shared in the next section. Relevant learning points from a Wikimedia Youth Salon is also incorporated into this report.

In addition, Jack Nunn (Director of Science for All) worked with a number of people to complete STARDIT reports, in order to test how appropriate and useful the data entry was. This involved a series of phone and video calls, followed by exchanging versions of STARDIT reports in order to create finalised versions.

Data from all these sources has been collated and organised into themes using qualitative thematic analysis. Event attendees were invited to ensure this report captured comments from the event. Further information about this data (including how it was collated and analysed) will be shared in the planned peer-reviewed paper 'Standardised Data on Initiatives (STARDIT): Beta Version'.

London Event Summary

On 1st October 2019, Science for All facilitated the first public meeting about 'Standardised Data on Initiatives (STARDIT)'. The event was facilitated by Jack Nunn (Director, Science for All) and hosted by the University College London Institute of Education, London.

Registration was free and open to anyone. People could join both in person and online. The facilitated discussion lasted three hours, with breaks. A detailed facilitation plan can be found in the supplementary materials.

Learning from the discussion has been incorporated into feedback from other sources and has not been attributed to individuals.

List of attendees

In person:

- **Jack Nunn** – Director, Science for All, Strategy Liaison and Editor for the WikiJournals, member of the Cochrane Advocacy Advisory Group, PhD candidate at La Trobe University, Melbourne (Australia)
- **Sandy Oliver -** Director of the Social Science Research Unit and Deputy Director of the EPPI-Centre, Professor of Public Policy at University College London, Editor of the journal 'Research for All'
- **Carolyn Thompson** - PhD Researcher, Institute of Zoology and University College London, Postgraduate Teaching Assistant and Lecturer, University College London.
- **Mick Mullane -** Innovation Lead, National Institute for Health Research Digital Office
- **Jim Elliot -** Public Involvement Lead, Health Research Authority (England)
- **Richard Stephens** - Patient Advocate, Co-Editor-in-Chief, 'Research Involvement and Engagement', National Cancer Research Institute 'consumer' representative

Online:

- **Chloe Mayeur –** Sciensano (Belgium)
- **Wannes Van Hoof –** Sciensano (Belgium)
- **James Ansell –** Consumers Health Forum (Australia)

The first 'STARDIT' selfie at the London event
Left to right: Jack Nunn, Sandy Oliver, Carolyn Thompson, Mick Mullane, Jim Elliot, Richard Stephens

Learning points from the public consultation

STARDIT as a project

- The principle of standardised reporting described by STARDIT is **useful across disciplines, this is 'unique'**
- STARDIT reports will be useful for a number of disciplines, including health research, environmental research, public policy, educational interventions and community arts projects.
- Many people don't know who to trust and one participant noted that 'most of our decisions are based on trust'. **STARDIT was identified as a way of sharing data that will facilitate people to critically appraise many kinds of data**.
- STARDIT is especially **helpful for people to self-assess research** and appraise it, including supporting **informed decision making about whether to participate.**
- STARDIT was identified as a way of reporting how people were involved in defining 'shared purpose', including defining outcome measures (for example, answering the question 'what does success look like and how will we measure it')
- STARDIT could provide **an independent way for researchers and policy makers to show how people have been involved in co-producing it**
- STARDIT was identified as **a helpful tool for international development**, including planning, reporting and evaluating initiatives(2)
- STARDIT was identified as **a helpful tool for people planning, reporting and evaluating initiatives**, including mapping preferences for involvement, reporting involvement and impacts from involving people.

Proposed collaborative way of working

- While the project is 'ambitious', the proposed collaborative way of working balances openness with efficiency
- In order to make STARDIT happen, it was suggested to 'start small' and 'think like a start-up'
- A number of partner organisations were suggested throughout the public consultation including Academic Health Science Networks (UK), The National Cancer Research Institute (UK), Independent Cancer Patients' Voice (UK), Clinical Trials Units (UK), Patient Focused Medicines Development (global), National Institute for Health Research (England), Good Things Foundation (UK and Australia), Google ('Scholar' team), National Institute of Health (USA), Patient-Centered Outcomes Research Institute (USA) and the James Lind Alliance

Authenticity and trust

"This is so global and so big – it comes back to trust, how do I trust the people who report data using STARDIT"

STARDIT will be assessed by an editorial board and eventually, open peer review. It will use indicators from public domain sources. However, the root problem of authenticity and truthful reporting remains for all peer-reviewed data. While STARDIT provides data to facilitate critical appraisal, ongoing work will be required to ensure the authenticity of data. Partnering with the Wikidata project will ensure data is linked and machine-readable. Assigning Digital Object Identifiers

to STARDIT reports will ensure that versions are immutable, but that the reports themselves can be updated should errors or inaccuracies be discovered.

Personal safety risks

Risks were identified with STARDIT for people who may share information or data which might have legal or safety implications. For example, data provided by members of the public about illegal activities (such as poaching or illegal logging) might incriminate individuals or put those sharing the data at personal risk. Ways of ensuring data is shared in ways which balance transparency with personal safety need to be carefully considered. China was identified by one researcher as an example of a country where special attention and cultural sensitivity would be required.

Life or death information

STARDIT was identified as a tool which could help people critically appraise information which might be life-saving or potentially lethal if incorrect. As well as medical information, this also includes information on Wikipedia pages about things such as edible fungi and plants(3).

STARDIT should have a transparent process for redacting information which might contribute to the destruction, poaching or killing of rare or threatened species, for example, not sharing detailed location information of rare species.

Sharing power

There is 'knowledge as power and powerful knowledge', STARDIT is a way of sharing both kinds of knowledge. Some 'power brokers' might not welcome knowledge sharing, transparency and scrutiny in certain areas and may actively resist attempts to share data and power. 'Power brokers' who might be resistant were identified as people working in government and for-profit organisations.

Knowledge translation

Understanding and measuring comprehension and knowledge translation are ongoing challenges in many disciplines. While STARDIT can report data on this, ongoing work will be required to ensure reporting is aligned with international best-practice. Partnering with organisations such as Cochrane and Campbell will help ensure the reporting tool is useful. STARDIT can report transformative learning as an impact, but this will require careful tailoring to each language and culture.

Diversity and inclusion

Ensuring the process for both involving people in the development of and for using STARDIT are inclusive will need continuous reassessment, potentially requiring a group of experts and advisors. In addition, as STARDIT is developed for languages other than English, groups of people specialising in linguistic and cultural diversity will need to be involved in ensuring STARDIT is appropriate, culturally safe and inclusive.

Technical considerations

Machine learning and 'artificial intelligence' could be employed to create reports. Wikidata is built for machine learning and provides an open, public domain and free way of sharing data that anyone can access, anywhere. After providing a way to host reports, multiple ways to submit them should be co-created.

Readability and plain English

The 'Standardised Data on Initiatives (STARDIT): Alpha Version' needs to be improved for readability and plain English. In addition, the purpose and scope needs to be explained more clearly. Tailoring communication to specific disciplines should also be considered. Future versions that might be translated into other languages will require co-creation with language communities to ensure they are comprehensible to as wide an audience as possible.

Systematic Searching

Future versions of STARDIT after the Beta version will require a systematic review in order to ensure that all appropriate data sources have been consulted. As this will require a significant investment of time from those involved in the STARDIT project, it was agreed that at this stage of the co-creation process, a 'mini-review' (published in the peer-reviewed WikiJournal of Science) was an appropriate intermediate step to ensure the current search strategy is appropriate.

Indigenous knowledge

A report by Science for All written for the Wikimedia Foundation identified that there might be systematic, technical and cultural barriers to incorporating the knowledge of indigenous peoples into Wikipedia and other peer-reviewed repositories(3). After additional meetings with staff from the Wurundjeri Woi Wurrung Cultural Heritage Aboriginal Corporation, it was agreed that it could be helpful to explore using STARDIT to co-create a way for indigenous peoples to share traditional and oral knowledge. STARDIT could be used to transparently report who created any content containing the knowledge, what tasks they had, how this knowledge was shared and any relevant concepts of 'owning' or 'property'. Members of Indigenous communities could work in partnership with the Wikimedia Foundation to create 'verified' users who formally represent relevant communities are have permission to share and verify knowledge (including stories, beliefs, medicine).

The report concluded that a detailed piece of research needs to be commissioned (potentially by the Wikimedia Foundation) to explore concepts of 'intellectual property' and 'owning knowledge', and how this respectfully interacts with the free knowledge and open access movements. Certain cultures have restricted, taboo or 'secret' knowledge(3). This can include culturally significant sites which may be at greater risk of vandalism if they are shared in the public domain. STARDIT needs to be co-developed with the Wikimedia Foundation and with indigenous peoples to ensure that a balance is struck between sharing, storing and preserving unique intangible culture, while also remaining sensitive to respective cultural practices and attitudes regarding 'ownership'.

Actions

1. Create a peer-reviewed scoping review to supplement the STARDIT beta paper, in preparation for a future systematic review.
2. Science for All to pay developers for creation of STARDIT report hosting. Create a project brief and invite developers to apply to create a beta version of STARDIT hosting.
3. Host more face to face and online events in other capital cities, including Canberra and Berlin.
4. Rewrite parts of the STARDIT paper to be clearer and in plain English.

Supplementary resources

Facilitation plan for public event – 1st October: London

Purpose of event

Create an opportunity for people from different disciplines to talk about standardised ways of reporting initiatives, including research, education and international development.

Aims

- Summarise what different disciplines are reporting about initiatives and how
- Suggest a common framework for reporting (STARDIT)
- Host a discussion about common challenges and generate ideas

Session	Summary	Instructions	Outcomes	Timing
Introductions	A chance to learn who is in the room, and what they hope to get out of today - and what the process for the afternoon is	Ask everyone in room and online to say what their area of expertise or knowledge is and why they've come today - **Online: Facilitator will summarise comments from people**	Everyone knows who is in the room and online.	15
Jack Nunn, Director of Science for All	A short presentation from Jack Nunn, Director of Science for All - about the learning from his recent projects, including his PhD about involving people in genomics research. A short summary of 'Science for All' and what led to STARDIT			10
Carolyn Thompson, Primatologist	A primatologist investigating small ape decline in China, Vietnam and Myanmar. She's working with local people, using participatory action research to investigate the patterns and drivers of critically			10

	endangered gibbon decline. She will discuss how STARDIT could be useful for recording impacts from this kind of work.			
Open discussion (including input via Zoom)		Ask people online to type thoughts or comments to be read out (also check Twitter #stardit). Ask people in the room to share initial thoughts, **summarise comments from people online.**	People online and in the room have contributed to discussion	5
Break - mingle - tell people online to log back on in either ten minutes to hear speakers or log back on at 2:10 to join the 'Idea Vortex' - **note Australians might be going to bed and say goodnight**				10
Reporting the what, who and how?	Short introduction to STARDIT with 3 different speakers leading discussions on how it could be used and improved.			
	Sandy Oliver - a personal and professional perspective (including thoughts on journals) - **lessons from successful reporting tools?**			7
	Richard Stevens - a personal perspective as a cancer patient and a professional perspective in relation to genomics research and on journals) **What would make people want to use this?**			7
	Jim Elliot - a personal perspective and a professional perspective in relation to the work of the Health Research Authority. **What support would people need to use STARDIT?**			7
Idea vortex	Using the 'Idea Vortex' model - a series of questions designed to find issues and create solutions	**Welcome back people online!**		50

Open discussion and break				10
Learning so far	A chance for anyone to speak about what has been learned so far, any reflections. Also a chance to map who's not involved who should be moving forward - and who will invite them!	**Invite comments from people online**		15
Agreeing tasks, actions and discussion areas	What actions have been agreed, what tasks and areas for further discussion	Explain how Loomio will be used going forward and how actions and decisions will be made	A list of actions, tasks and decisions to be posted on Loomio.	15
Open discussion - tea - cake - 'networking'				20
Formally close event 4pm. Adjourn to nearby pub.				

Additional Discussion Points

These additional discussion points were used to supplement the discussion:

- Can anyone write STARDIT reports? People unaffiliated with projects? Can this be one data-line that contributes to a 'living report' - in other words, could people report on behalf of organisations (like people can write Wikipedia pages about organisations without their approval)
    - Solution could be that reports make it clear when people from the organisation have been involved - verified (tick like on twitter?)
- How should peer review work?
    - In the short term, it will have to be an editorial board (volunteers associated with the WikiJournals) - we will use the existing processes of the WikiJournals for the Alpha version and Beta version
    - In the longer term - post beta version - it should be an open peer review process. For discussion
    - Peer review needs to ask the question is there evidence/data to back claims in STARDIT report - does it require some kind of standard critical appraisal tool?
- In the longer term STARDIT could 'score' projects
    - STARDIT scored- a peer reviewed score for an initiative which scores it on criteria including 'power sharing/involvement', data sharing, dissemination and translation
    - Scoring could be based on 'is there a data source for this item' so that it is not subjective (Binary yes or no on indicators of involvement)
    - Scoring continually reviewed but must be future-proofed so historical scores still have validity and use
    - This function would likely require funding/grant etc to support infrastructure - while peer reviewing would be voluntary the process of editorial control and back end would need not-for-profit investment.

STAR	Dissemination	Involvement	Translation
4.9	5	2	3

- Can things like 'documentaries' be included - who made it, who did what, who funded it? Would this be a category of 'educational intervention' - allowing documentaries to actually measure impact
- Risk of confusion with reporting guideline: STARD http://www.equator-network.org/reporting-guidelines/stard/
    - Not considered an issue by attendees
- Create API for other journals etc to use with their site? Create badge
- Partners get accredited to improve participation and recruitment
- Citing Aboriginal stories - create STARDIT report for story?

References

1. Nunn JS, Shafee T, Chang S, Stephens R, Elliott J, Oliver S, et al. Standardised Data on Initiatives - STARDIT: Alpha Version.
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3. Nunn J. WikiJournal Youth Salon Evaluation Report - Science for All [Internet]. 2019. Available from: https://web.archive.org/web/20191219020842/https://meta.wikimedia.org/wiki/File:WikiJournal_Youth_Salon_Evaluation_Report_-_Science_for_All.pdf