Health & Medicine | Bettina Ryll, Gilliosa Spurrier & Violeta Astratinei

V2A2

A tool to promote patient agency through effective patient information

The Melanoma Patient Network Europe (MPNE) attaches particular importance to effective scientific patient information. As a patient community with a keen research interest, the network has over the years developed its own methodology and standards on how to rapidly and accurately share scientific information even across language boundaries. Bettina Ryll, Gilliosa Spurrier and Violeta Astratinei, founders of MPNE, have developed the tool V2A2, hoping it will be of use to all those passionate about effective educational content for patients and patients advocates.

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The Melanoma Patient Network Europe, MPNE, is a network of European Melanoma patients and their family members. Melanoma has seen significant therapeutic progress in the last decade, from a situation of median survival of 6–9 months to about half of all patients with advanced Melanoma now surviving the disease. In a rapidly evolving treatment landscape, education about new treatment options including clinical trials was and remains critical for the patient community. As unfortunately still too many Melanoma patients die, research remains an important focus area of the network. Research engagement – be it the selection of a clinical trial, the review of clinical trial designs or research protocols, or the drafting of project proposals – requires a high level of scientific understanding. MPNE therefore places particular importance on scientific education and has over the years developed its own methodology to rapidly and accurately disseminate relevant research findings across its network. For example, scientific information on any of MPNE's patient forums needs to be referenced and the network provides continuous training on how to access and read scientific articles.

MPNE's ultimate aim is to increase what the advocates themselves refer to patients' *agency*, the ability to make informed decisions regarding their own health. Bettina clarifies: "We prefer the concept of agency over the more commonly used 'patient empowerment' because of its directionality: the actor is the patient. Patient empowerment assumes a helpless patient waiting to be empowered by a benevolent outsider. Agency describes an autonomous patient assuming responsibility and taking action."

V2A2: CODIFYING EDUCATIONAL CULTURE IN A TOOL

In 2018, MPNE joined Share4Rare, a project funded by the European Union with the aim to facilitate data sharing between patients in a secure and non-commercial environment. Share4Rare's managed research feature allows to rapidly initiate research projects with validated participants, ethics board reviewed projects and advanced data protection securing patients' best interests. It quickly became apparent that Share4Rare would require patients to understand the value and importance of research in order to engage – and that MPNE's organically grown network scientific culture would not be easily transferable to a new community. V2A2 therefore became MPNE's effort to codify their learnings about what constitutes effective patient information in a scientific context as a multi-purpose tool that could be used to either directly review existing patient information material or to educate about the four domains that the advocates has identified as highly relevant: *validity, verifiability, accessibility* and *agency* that then became *V2A2*.

It is important to note that validity and verifiability stand in natural tension to accessibility on one and agency on the other side and therefore need to be carefully balanced for optimal results. For example, in the desire to create accessible content, an author might be tempted to omit technical terms and references. Technical terms are vital to searching for correct information and key to avoiding fake news while omission of references prevents the reader from verifying the trustworthiness of the information, ultimately limiting agency. In contrast, a highly referenced text might be easily verifiable, but often

negatively affects readability. This in turn reduces the accessibility of the text, curtailing agency yet again.

TOOL DEVELOPMENT

In addition to the documentation and a V2A2 user guide, V2A2 consists of a 20-item checklist against which a given text is rated. Items are scored for presence or absence and positive ratings summarised, with a high score out of 20 indicating a well-written patient information text. MPNE now uses the tool to self-evaluate the educational content it produces. If consistent results are required, they recommend several (3–5) parallel and independent evaluations, followed by a comparative analysis as certain items contain a degree of subjectivity. Overall, V2A2 is intended as a guide, not as an absolute measure and has proven equally useful as an educational tool to illustrate factors that positively or negatively influence the educational value for patients.

V2A2 v1.0 was developed by Bettina Ryll, Gilliosa Spurrier and Violeta Astratinei, and user-tested during the annual network conference MPNE2019 in Brussels. Based on user feedback, V2A2 was amended to the current version (v1.1.) and the tool complemented by the V2A2 user-guide. V2A2 is covered by a CC BY SA (Creative Commons Attribution-Share Alike) licence and can be easily adapted for personal branding.
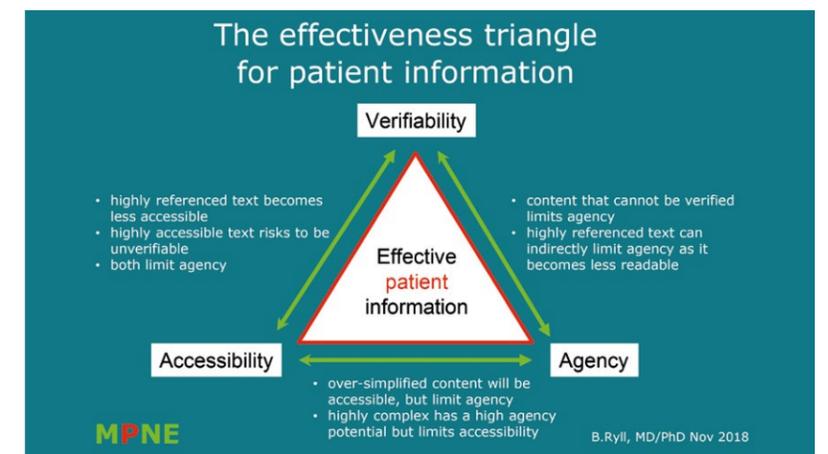
V2A2 IN DETAILS

V2A2's 20 items cover the four domains of validity (items 1–3), verifiability (items 4–9), accessibility (items 10–18) and agency (items 19–20).

VALIDITY

In addition to completeness and accuracy, the validity of medical and scientific content is critically dependent on how recently the content was generated. All content therefore should be dated and reviewed regularly. Bettina suggests providing content with a 'valid until' date and the date of the prospectively scheduled next review, a process facilitated by automation.

- Item 1: Is the content complete and accurate?
- Item 2: Is the content dated, both original and last review?

The effectiveness triangle for patient information

Verifiability

- highly referenced text becomes less accessible
- highly accessible text risks to be unverifiable
- both limit agency

Effective patient information

- content that cannot be verified limits agency
- highly referenced text can indirectly limit agency as it becomes less readable

Accessibility

Agency

- over-simplified content will be accessible, but limit agency
- highly complex has a high agency potential but limits accessibility

MPNE

B.Ryll, MD/PhD Nov 2018

- Item 3: Is the next review date scheduled?

VERIFIABILITY

Content needs to be easily verifiable to allow for cross-referencing and independent verification. Items 4–6 address whether claims are appropriately referenced, e.g. citing a correct and credible source and stating how easily traceable it is. Ideally, references should be provided as direct links to an open access version of the scientific article as readers might

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not be familiar with PubMed and are unlikely to have institutional access to scientific literature. Items 7–9 cover the authorship of the article – authors should be identifiable by their full name, provide credentials, e.g. a link to their affiliation to an academic department and potential conflict of interests.

- Item 4: Are all claims supported by references?
- Item 5: Are the references valid?
- Item 6: Are the references easy to trace?
- Item 7: Is the name of the author indicated, both for original and every review?
- Item 8: Are professional or other credentials of the author clearly stated?
- Item 9: Are there any potential conflicts of interest?

ACCESSIBILITY

The technical nature of scientific or medical publications poses a considerable challenge for a lay readership. V2A2 therefore analyses three aspects: the technicality of the language, general readability for factors known to affect the accessibility of a text and the overall structure as particularly relevant for web-based content. To verify the *technicality* of the language, items 10–12 examine whether all abbreviations are either replaced by the full-text version or – if that is impractical – explained and

then distinguishes between unnecessary technical jargon that should be removed and relevant technical terms that need to be explained.

For example, 'the cancer metastasizes' can be replaced without loss of information by the more accessible 'the cancer spreads throughout the body'. In contrast, terms with relevance for prognosis, e.g. 'ulceration' in Melanoma, treatment decisions e.g. 'progression' or describing side effects e.g. 'colitis' or 'hypophysitis' under therapy with checkpoint inhibitors should be explained and not replaced as patients are likely to encounter them in their interaction with their medical team and awareness of the term greatly increases the likelihood of retrieving relevant information online.

- Item 10: Are all abbreviations explained?

Patient Information Review Tool v1.1

yes   no

Validity
- Is the content complete and accurate?
- Is the content dated, both original and last review?
- Is the next review date scheduled?

date and review

Verifiability
- Are all claims supported by references?
- Are the references valid?
- Are the references easy to trace?

references

- Is the name of the author indicated, both for original and every review?
- Are professional or other credentials of the author clearly stated?
- Are there any potential conflicts of interest?

author

Accessibility
- Are all abbreviations explained?
- Has unnecessary technical jargon been removed?
- Are relevant technical terms explained?

technicality

- Are sentences shorter than 20 words?
- Are words, with the execption of relevant technical terms, simple, with fewer than 4 syllables?
- Are sentences written in the active voice?
- Have all unnecessary quantifiers been removed?

readability

- Is the text clearly structured?
- Are paragraphs no longer than 300 words?

structure

Agency
- Is the text respectful of the reader?
- Does the text enable readers to continue learning on their own or otherwise take action?

intent

Share4Rare

CC by MPNE SA

/20 score

For patients, knowledge means protection and influence in research. Education is the key and V2A2 the accelerator to that knowledge.

- Item 11: Has unnecessary technical jargon been removed?
- Item 12: Are relevant technical terms explained?

Item 13–16 evaluate current recommendations for increased *readability* such as the Readability Test Tool (https://www.webfx.com/tools/read-able/), the Gunning Fog Index (http://gunning-fog-index.com/) and the Hemingway App (http://www.hemingwayapp.com/), including the lengths of words and sentences, the use

of the active voice and the removal of all unhelpful quantifiers such as 'some', 'few', 'rather'. Online tools for readability checks can be useful but are punitive for essential technical terms so they require the removal of these prior to analysis.

- Item 13: Are sentences shorter than 20 words?
- Item 14: Are words, with the exception of relevant technical terms, simple, with fewer than 4 syllables?
- Item 15: Are sentences written in the active voice?

- Item 16: Have all unnecessary quantifiers been removed?

As text structure contributes to the accessibility of text as well as the learning experience of the adult learning skimming for relevant information, items 17–18 evaluate overall structure as well as paragraph length.

- Item 17: Is the text clearly structured?
- Item 18: Are paragraphs shorter than 300 words?

AGENCY
Provided content should increase readers' agency and reflexivity, meaning their capacity to define and shape their own priorities, preferences and norms (high reflexivity) instead of merely reacting to a given surrounding (low reflexivity). Texts directed at patients are often written in a patronising or infantilising tone which is disrespectful and demoralising. Items 19–20 therefore evaluate whether material is respectful towards the readership as well as in how far it encourages and facilitates independent further learning as critical factors for assuming agency.

- Item 19: Is the text respectful of the readership?
- Item 20: Does the text allow readers to continue to learn on their own, take other action and does it increase their range of options?

SHARE4RARE: SHARING TO HELP PATIENTS WITH RARE CONDITIONS
After having seen the impact of accessible scientific knowledge on their own network, the MPNE advocates are keen to share their learnings with the wider patient community. In particular, they want to help patients affected by rare conditions who might not be so lucky to have a supportive community behind them. Violeta, founder of Melanom Romania, states: "For patients, knowledge means protection. Knowledge also means influence in research in your disease area. And education is the key and V2A2 the accelerator to that knowledge!" The advocates are now working towards their next goal: establishing a Share4Rare research platform that enables patient communities to initiate and run their own, validated research projects.

Behind the Research

Dr Bettina Ryll
Gilliosa Spurrier
Violeta Astratinei

E: bettina.ryll@mpneurope.org
E: gilliosa.spurrier-bernard@mpneurope.org
E: violeta.astratinei@mpneurope.org
W: http://www.melanomapatientnetworkeu.org/

Research Objectives

MPNE are developing a user-friendly tool that helps promote patient agency by providing means to assess patient information for their quality.

References

Share4Rare [online]. Available at: https://www.share4rare.org/ [Accessed 10/07/2020]

Personal Response

What inspired you to create V2A2?

" We have learned in Melanoma that knowledge protects patients. We as a Melanoma community therefore spend considerable time and effort on keeping up to date ourselves and sharing scientific information via diverse patient forums and across language barriers. As a result, our forums have become safe places for learning and exchange. And thanks to the overall level of knowledge, we as community have become widely engaged in research projects ourselves. Our hope is that V2A2 will allow other communities to quickly replicate our learnings- and with that, keep many other patients safe! "

Detail

Bettina Ryll
Melanoma Patient Network Europe
Fjällbo Selknä 152
75597 Uppsala, Sweden

MPNE

Bio
The Melanoma Patient Network Europe (MPNE) was founded in 2013 by Bettina Ryll. MPNE functions as an organically growing multi-dimensional network system that applies the diverse learnings – from gene networks over learning techniques to learn start-up principles – to make a difference in Melanoma.

Funding
This project has received funding from the European Union's H2020 research and innovation programme under grant agreement No 780262.