

Group N° 6: Defining reliable information online and protecting users

Break-out sessions

ESC Education Conference – 31 Jan - 1 Feb 2018

Current use, challenges and limitations 1

Group 6: Defining reliable information online and protecting users

- **Reliability of online information and consequences of that information should be a priority**
- We can't define total reliability but we can minimize the unreliability
 - Information not made up, unbiased content, balanced, evidence based vs. eminence based, vetted source, vetted by my institution (vetted by expert)
- Current use:
 - **For patient and HCP**
- Advantages:
 - Accessibility / ease of use / easier for the HCP as patient is informed / quality control
- Challenges:
 - **The ESC and similar Scientific Societies: still the most reliable source but** there are limitations (+++).
 - Publication bias, research fraud, industry sponsorship of editors / authors → conflict of interest.
 - **ESC is not a Patient focused organization** (no clear patient dedicated space / ACC-AHA) (+++).
 - How to communicate and substantiate simple / basic information for the patient?
 - Language of the material provided by ESC (English) (+/-).
 - **ESC doesn't come among first choices on search engines (Google...).**
 - Dr Google provides unfiltered medical information.
 - Heterogeneity of training depending on country.

Current use, challenges and limitations 2

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- Protecting users:
 - Cyber-trolling / abuse for online activities (including education / sharing information) → has to be policed accordingly.
 - Risk that in future logbooks and reflective practice may legally be used against HCP.
 - Patient confidentiality should be maintained when sharing online information.
 - Not using guidelines as standard (inability to apply / misinterpretation).

Opportunities for the future & role of the ESC 1

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- **Guidelines and high-quality materials to educate HCP.**
 - Reliable source of high-quality information, but quality must be maintained.
 - Timing / updating were mentioned an issue.
 - Generation of meta-analyses and registry data discussed /have a statistical commentary for major papers.
- **Training materials/educational materials on the ESC website.**
 - More intelligent / problem based search within the website.
 - Educate HCP on how to read the main messages of Guidelines.
 - Need for more specific training in interpreting statistics.
- **Low visibility of ESC materials on the internet (search engines).**
 - Marketing investment / promotion (for the patient).
 - Include links to **reliable** pages that could provide reliable patient information.
 - Space dedicated to the patient (similar to the www.heart.org).

Opportunities for the future & role of the ESC 2

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- **A more patient-centred approach.**
 - **ESC producing Guidelines for patients (potentially) / addenda – appendix at least.**
 - NCS needs to deploy the information to the patient.
 - Better visibility through Google search engine.
 - Include links to pages that could provide reliable patient information.
 - Apps with curated content for / dedicated to patients.
- **Guidelines on handling data and social media.**
 - What to do when it goes wrong (ESC congress – online information).
 - Transparency about risks / benefits and openness to encourage people to report them.
 - Training on communication with patients so they can make informed decision.
 - Local patients' associations to provide additional information to help patients.
 - Practical approach on medical statistics or other subjects.
 - **Position of ESC on handling/ counseling of legal issues.**

In pictures:



EDUCATION!!
AT THE TOP?!

Statistical training

WHAT IS RELIABLE?

I have a stent. But I read on google that I shouldn't use it?



OK, I should use ESC guidelines I guess??!



→ Guidelines??
→ Journals???
↳ Yes, but which??
[Confused face]



→ DON'T WORRY GUYS!
WE ARE HERE TO ENLIGHTEN YOU WITH OUR WEBSITE SOON!
JUST FOR YOU (❤️)

RELIABLE?

YES

NO

We don't know what to do?



→ Heart failure patients have some concerns??

Group 6 Team

