Group Nº 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??

Heart failure patients have some concerns??

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?!
Group 6 Team