STANDARDS OF EXCELLENCE FOR PATIENT ORGANISATIONS

SPAEN ANNUAL CONFERENCE – JANUARY 2020

ABOUT CAMPAIGNING FOR CANCER

Our Vision

To create a South Africa where people affected by cancer receive fair, appropriate, timeous, respectful and quality treatment and care.

Our Mission

1. To ensure that the patients' rights are protected by:

- Ensuring dialogues amongst role-players.
- Facilitating solutions with regard to cancer prevention and treatment.
- Representing patients with regard to:
  - policy
  - healthcare costs
  - healthcare delivery
  - understanding the cancer landscape

in a manner that ensures that all stakeholder positions are considered.

2. To ensure that South Africans are informed & educated about cancer and their rights as patients.

CAMPAIGNING FOR CANCER

This message
is so simple,
yet it gets forgotten.
The people living
with the condition
are the experts.

Michael J Fox
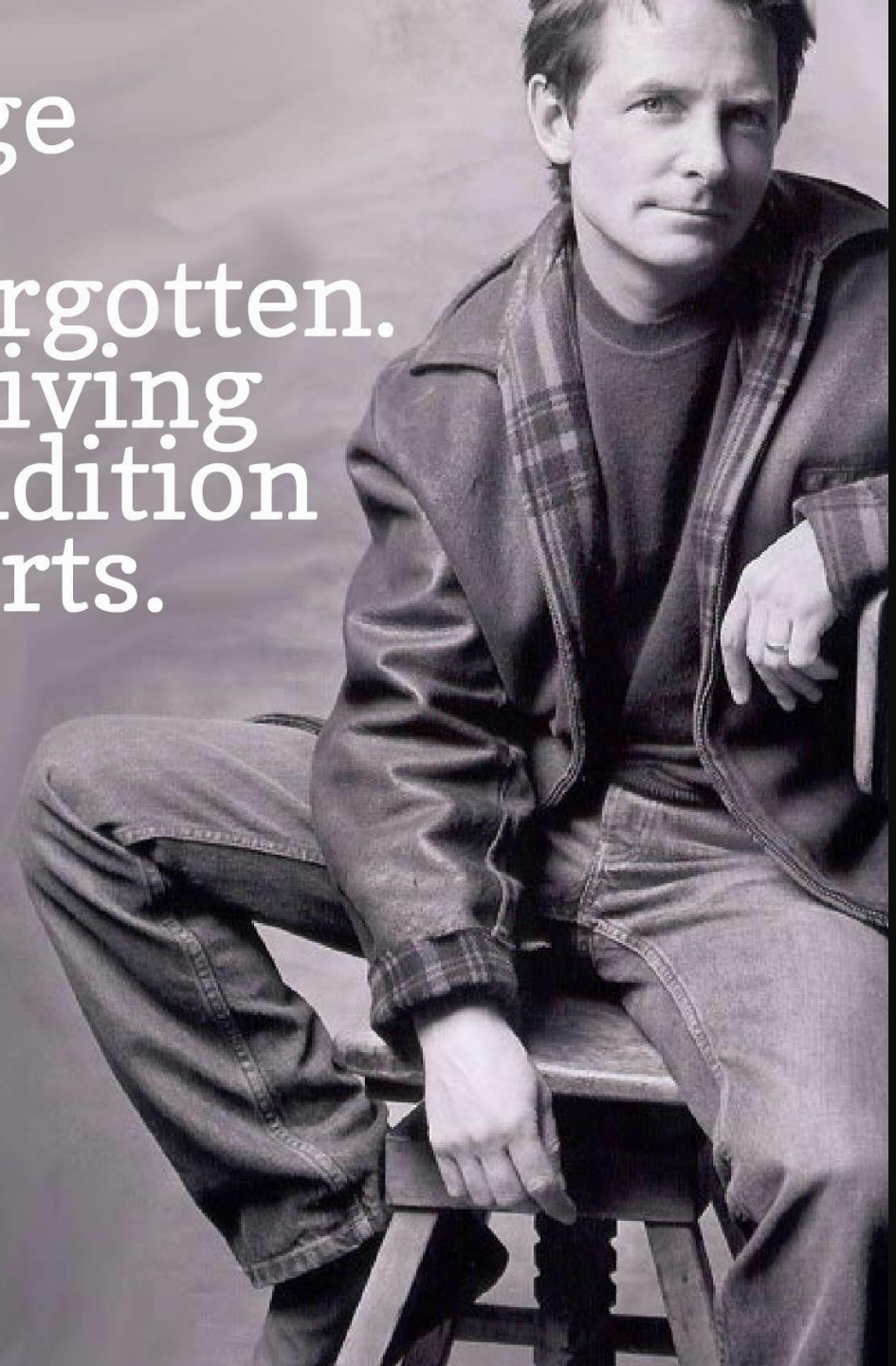
Characteristics embodied in Governance:

- Discipline
- Transparency
- Independence
- Accountability
- Responsibility
- Fairness.
- Social Responsibility

Characteristics embodied in Governance

Elements of Governance

- **Boards and Directors**

- **Accounting and Auditing**

- **Risk Management**

- **Internal Audits**

- **Integrated Sustainability Reporting**

- **Compliance and Stakeholder Relationships**

- **Business Rescue**

- **Fundamental and Affected Transactions**

- **IT Governance**

- **Alternative Dispute Resolution**

Governance

- ❑ Board Operational Standards
- ❑ Code of Ethics
- ❑ Communication Guidance
- ❑ Complaints Policy
- ❑ Conflict of Interest Policy
- ❑ Grievance Policy and Procedure
- ❑ Guiding Principles for Advocacy Excellence
- ❑ Policy for Volunteers
- ❑ Policy for working with Corporations
- ❑ Policy for Working with Government
- ❑ Policy for Working with Health Care Professionals
- ❑ Policy for Working with Patients, Caregivers and Families
- ❑ Privacy Policy

Information Standards

- ❑ Commitment Statement
- ❑ Definition of Credible Medical Information
- ❑ Policy for Editorial Process

Organisational Process & Continuity Planning

- ❑ Board Development Guiding Principles
- ❑ Computer Usage Policy
- ❑ Knowledge and Information Sharing Policy
- ❑ Risk Management Plan Checklist
- ❑ Policy for Media Relations and External Relations
- ❑ Social Media Policy
- ❑ Staff Development Guiding Principles
- ❑ Strategic Planning Process

Financial Accountability and Fundraising

- ❑ Anti- bribery Policy
- ❑ Financial Accountability Policy
- ❑ Fundraising Policy

5 Basic Good Governance Practices

- ❑ **Maintain minutes** of all board meetings
- ❑ **Annually review a written policy** and complete a questionnaire about **conflicts of interest** and document in minutes of board meetings when the policy is invoked.
- ❑ **Approve the executive director/CEO's compensation and benefits**, and document how the board determined that the compensation is appropriate, and not excessive.
- ❑ Require the board to **review a copy of the AFS** before they are filed.
- ❑ **Disclose** to the public the non-profit's **three most recently filed annual returns** with the Tax Authority, as well as incorporation certificate and registration.
- ❑ **Anti- bribery** Policy
- ❑ **Financial Accountability** Policy
- ❑ **Fundraising** Policy

CAMPAIGNING FOR CANCER

C4C Compliance Document

Guiding Principles for Developing Effective Marketing and Patient Education Materials

January 2018

Scope of Document

This document is to be used as a preliminary guidance for marketing and design agencies when creating Marketing and Patient Education Materials (Organisational & Disease / Patient Education).

Campaigning for Cancer's (C4C's) Policy on Confidentiality and the use of personal information belonging to patients has to be regarded when developing any intellectual properties which include the use of patient information and/or visuals.

What are Patient Education Materials?

The primary purpose of patient education material is to improve health literacy amongst members of the public (the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions) and to empower and assist citizens, patients, caregivers, users of medicines to make informed decisions about the appropriate, safe and effective manner in which to self-manage their general health, make informed decisions regarding prescribed treatments of medical conditions and direct them to community resources that will assist in this health journey.

What are Patient Education Materials? (continued..)

There is a range of sources of patient education materials and information that can be made available to the public, including:

- Verbal information (from health care professionals).

- Written information directly supplied with individual medicines by pharmaceutical companies, pharmacists, and other health care professionals (e.g., medicines labelling and information leaflets or package inserts).

- Written information available from patient or health care professional organisations, governmental and non-governmental health organisations, pharmaceutical companies and other organisations that communicate with patients.

- Websites (i.e., providing information on medicines or health conditions).

- Digital resources such as mobile health (m-health) apps and social media (e.g., Twitter, Facebook, Wikipedia and YouTube).

Relevant documents / codes

The following reference documents where referenced when developing this documents:

- International Federation of Pharmaceutical Manufacturer & Association (IFPMA) - *www.ifpma.org* :
    - Code of Practice, 2012.
- Marketing Code Authority (MCA):
    - SA Code of Marketing Practice v10, November 2016.
    - Guidelines to the Code of Marketing Practice, February 2015.
- Internal C4C documents:
    - Manual Prepared In Accordance With Section 51 of the Promotion of Access to Information Act, Act No. 2 of 2000, and in due course , the provisions of the Protection of Personal Information Act No. 4 of 2013 ("The ACT").
    - C4C internal Social Media and Internet policies.
- Patients' Rights Charter .
- Chapter 2 of the National Health Act No. 61. of 2003.

Accuracy, balance, and fairness

- Any material developed for the education of the public or a patient must ensure that it is at all times accurate, balanced and fair.

- **Accuracy**
  - Promotional material has to be clear, balanced and complete.
  - Information and claims about side effects must reflect available evidence or be capable of substantiation by clinical experience.
  - All pieces will be reviewed at least every 2 years and sooner if substantive changes have occurred in the topic, particularly regarding the accuracy and completeness (including resources).

Accuracy, balance, and fairness

- **Balance**
  - Information, and claims must be accurate, objective and unambiguous and must be based on an up-to-date evaluation of all the evidence.
  - Comparisons are only possible if they are not misleading and are capable of substantiation.
  - Care has to be taken when using superlatives and the words "unique", "ultimate", etc.
  - The word "safe" or phrases containing reference to safety must not be used without adequate scientific substantiation.
  - Artwork must not mislead and not detract from safety aspects.

Accuracy, balance, and fairness

- **Fairness**
  - Content for CME activities must be fair, balanced, objective and designed to allow the expression of diverse and recognized opinions.
  - The products and activities of other health-related organisations must not be disparaged in any way.
  - Promotional material must not imitate the services, products or devices, copy slogans or general layout adopted by other healthcare organisations in a way that is likely to mislead or confuse.
  - It must not be stated that a health product has no side effects, toxic hazards or risks of addiction.

Suitability and taste

- All material and activities must recognize the special considerations relating to the promotion of the health product and must not be likely to cause offence.

- Be aware of language, customs, and values to create a culturally sensitive and effective tool.

- The name or photograph or film/DVD etc. of a member of a health profession must not be used in any way that is contrary to the conventions of that profession.

- Claims must not cause offence on the grounds of race, religion, sex or disability.

- Text containing medical terms that are multisyllabic should be written at the 6th-8th grade reading level and terms need to be defined, where appropriate. Text without medical terms, should be written at the lowest reading level possible to convey the subject.

- Adult learners prefer content that will help them solve problems rather than just learn medical facts.

- Content of greatest interest will be that related to behaviours to help solve problems or avoid or control disease.

Style and format

- Design and copy development of education material must not surpass the accuracy, comprehensiveness, readability, ability for the material to be understood and acted upon by the reader.

- Specifically the following areas need special attention:
  - Use of pictures and photos,
  - Visual and graphic design elements, and
  - Language, vocabulary and style of sentence construct.

Style and format

- Use of pictures and photos:
  - Use pictures and photos with concise captions. Keep captions near the graphics.
  - Number the sequences of images and captions.
  - Position pictures on the same page adjacent to the related text.
  - Use visuals as much as possible of anatomical features of the specific system that relates to the patient's problem.
  - When showing internal body parts, display the outside of the body for reference. Avoid cutting off body parts.

Style and format

- Visual and graphic design elements:
  - Present one message per visual.
  - Create visuals that help to emphasize or explain the text.
  - Simple illustrations or line drawings often work best, please note that not all audiences understand cartoons.
  - Show readers the actions you expect them to take.
  - Avoid images that show what the reader should **<u>not</u>** do.
  - Use images that are likely to be familiar and easily recognized by viewers.
  - Focus efforts on key bullet points of "must know" information.

Style and format

- Language, vocabulary and style of sentence construct, specific suggestions include:
  - Use the active voice, e.g.: "you will have a blood test" rather than "blood tests will be done."
  - Write as though you are talking, using personal pronouns like "you" and "your."
  - Write as though you were talking to a friend. A conversational style has a more natural tone and is easier to read and understand.
  - Write paragraphs with no more than two or three sentences with one key point per paragraph.

Style and format

- Language, vocabulary and style of sentence construct, specific suggestions include:
    - Use analogies familiar to your audience. *Feel for lumps the size of a pea,* instead of, *Feel for lumps about 5 to 6 mm in diameter.*
    - Be clear and specific so that readers don't have to guess or assume what to do. For example, say "take a ten-minute walk every day" rather than "exercise moderately."
    - Avoid multi-syllable words if possible. For example, *join* rather than *participate.*
    - Use common, simpler words. For example, *choice* rather than *decision* and *often* instead of *commonly.*

Style and format

- Language, vocabulary and style of sentence construct, specific suggestions include:
    - Sometimes you will not be able to use simpler words. For example, if you substitute *air* for *oxygen,* you can drop the text reading level, but it is not an acceptable substitution*.*
    - Include a definition and show how to pronounce difficult but critical medical terms or concepts. For example: "bronchitis (bron-KI-tis), a disease that makes you cough."
    - Choose one term and use it throughout the piece. Use the same form of a word consistently. For example, don't switch between *surgery* and *surgical procedure*.

Style and format

- Language, vocabulary and style of sentence construct, specific suggestions include:
  - Avoid abbreviations and acronyms unless common to lay public and defined. If used, spell the word or entire term first and follow with the acronym or abbreviation in parentheses immediately behind.
  - Be careful about words like *may, might*, or *suggest* as these may be difficult to understand.
  - Be careful with subjective words such as *rarely* or *often*.
  - Avoid use of contractions such as don't.
  - Short sentences are generally preferred.
  - Use visual terms such as "runny nose" and "redness".

Transparency

- Printed promotional materials for medicines must use the active ingredients, as brand names can introduce bias.

- All material relating to health products and their uses, which is sponsored by a company, must clearly indicate that the company, organisation or individual is sponsoring it.

- Market research material need not reveal the name of the company, organisation or individual involved but must state that a company, organisation or individual sponsors it.

- Clearly state when the patient needs to call the doctor and what phone number to call.

- Clearly list the author of the material and their contact details, in this case C4C.

Off-Label Use / Promo to Public

- Product promotion must be consistent with the label and package insert.

- Only registered medicines and medical devices may be promoted.

- Promotional messages of products have to be referenced to the approved label or by scientific evidence.

- Public Disease Awareness Campaigns must not promote specific pharmaceutical products.

Referencing / Quoting

- When promotional material refers to published studies, clear and complete references must be given.

- Quotations relating to a health product taken from public broadcasts, for example radio, television or Internet, and from private occasions, such as medical conferences or symposia, must not be used without the written permission of the speaker.

- Referencing should be standard recognised by well respected, credible scientific journals and preferably those that are open access. Avoid commercial sites as much as possible.

- Online referencing must include websites well regarded and compliant to the Health On the Net (HON) Code.(https://www.hon.ch/HONcode/)

- Quoting a medical practitioner Key Opinion Leader (KOL) can only be made if they are registered in the country.

Disclaimers

Include standard C4C disclaimer for all patient education pieces as follows:

"This information and content is for educational purposes only. This information should not be considered as medical advice. It is not to be used in place of a visit with a doctor, nurse or other healthcare professional. If you have questions about your individual medical situation, please consult with your healthcare professional."

Copyright / Licenses

- If using patient or caregiver testimonials, the C4C a "Consent & Release Form" has to be signed to secure right and permission to copyright, use, re-use, publish and re-publish any materials (photos, pictures, videos etc.)

- If a user upload materials on C4C Website a "Terms & Condition Form" has to be signed to secure free-of-charge, unrestricted and non-exclusive unlimited license to display, use, modify that user content.

Checking if you have ticked all the compliance boxes?

- For each of the following criteria, tick yes or no. If you feel the category is not applicable, tick N/A. In this case, please provide a in comment/explanation or add any other comments.

Criterion	Yes	No	N/A	Comment / Explanation
CONTENT				
Medically accurate and up to date.				
Purpose clearly stated.				
Important and relevant (e.g., fills a gap in C4C or Civil society resources.)				
Well organised.				
Scope and level of detail are appropriate.				
Culturally sensitive for target reader(s).				
Proposed title clear and appropriate.				
Summary of key points and action steps provided.				
Appropriate resources with functional links.				

Checking if you have ticked all the compliance boxes?

- For each of the following criteria, tick yes or no. If you feel the category is not applicable, tick N/A. In this case, please provide a in comment/explanation or add any other comments.

Criterion	Yes	No	N/A	Comment / Explanation
WRITING STYLE				
Reading level (aim for Grade 6-8 or lower grade level.)				
Style (generally in an active voice, clear)				
Vocabulary (limit or define jargon, use common words)				
Tone is informative, friendly (not paternalistic or judgemental.)				
No conflict of interest or ethical concern.				
Appropriate length				

Checking if you have ticked all the compliance boxes?

- For each of the following criteria, tick yes or no. If you feel the category is not applicable, tick N/A. In this case, please provide a in comment/explanation or add any other comments.

Criterion	Yes	No	N/A	Comment / Explanation
GRAPHICS				
Appropriate match to content.				
Illustrations (simple, relevant, familiar, captions clear if applicable)				
Lists, tables (simple, easy to understand, necessary.)				