



INTERNATIONAL DIABETES FEDERATION
LANGUAGE PHILOSOPHY
TECHNICAL DOCUMENT



**International
Diabetes
Federation**

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare with respect to this Language Philosophy.



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OVERVIEW OF THE DEVELOPMENT PROCESS

A structured literature review was undertaken to determine words and language commonly used to refer to people with diabetes. Key search terms were diabetes, language, words, effects, physical, wellbeing, health, behaviour and various combinations of these words. Electronic databases searched were: GoogleScholar, Ovid, Medline; PsychINFO, CIINAHL PubMed, CLEARPOND, MCWORD, WordNet, Wordplay. The search was limited to publications in English.

The abstracts of relevant articles were obtained and read to determine whether they were related to language and the effects on health and wellbeing and/or diabetes. Full texts of papers that met these criteria were obtained. These papers were read and analysed systematically to detect frequently occurring words used to refer to or about people with diabetes (see tables 1 and 2).

The list of words was then used in informal discussions and interviews with people with diabetes from a range of sociodemographic settings, age groups, types of diabetes, durations of diabetes, treatment mode and complication status. The words were also used in the vignette on page 5 written to illustrate the pervasive nature of language and its effects on people with diabetes.

TARGET AUDIENCE

The target audience is IDF Board members, Board Committees, Consultative Sections, and Expert Working Groups, office staff including the Communications Team, Regional Council, Regional Offices and members, general and diabetes professional associations, diabetes consumer organisations, corporate partners, Diabetes Voice, Diabetes Research and Clinical Practice and other publications, people with diabetes and health professionals, generally.

INTRODUCTION AND RATIONALE FOR WRITING AN IDF LANGUAGE PHILOSOPHY

Written and spoken language is part of the every day work of the International Diabetes Federation (IDF). English is the official language of the IDF. However, English is not the first language of many health professionals, people with diabetes and organisations with whom the IDF works and communicates. In addition, countries that regard English as their first language do not necessarily speak or write English using the same words and grammar.

There is no single agreed definition of 'language.' Language and grammar constantly evolve to accommodate new technology, inventions, research and societal change. Such changes add to the complexity of language. The IDF Language Philosophy was developed to help people working for and/or communicating with the IDF to use appropriate language and write clear English using appropriate syntax, punctuation, active language, and to avoid obscure and discriminatory language.

Language influences the way people:

- View, experience and remember events and the associated emotions;

- Decide relationships between cause and effect;
- Understand written and spoken information (words, symbols and numbers);
- Take risks;
- Think about themselves and other people and about diseases (Boroditsky 2003, Diabetes Australia 2011).

Different parts of the brain are involved in processing different aspects of verbal and written language (Crystal 2006) and in social cognition, which is important to communication and interpreting facial expressions and gestures (Johnson 2011). In fact, unborn babies recognise their parents' voices when they are in the womb and become attuned to their speech patterns as well as their voices (De Casper 1986, James 2010). The fetal brain is capable of discriminatory accuracy (learning and remembering auditory experiences (James 2010), which could be a form of subliminal messaging.

These points are compelling reasons for writing an IDF Language Philosophy about language; however, the rationale for writing such a Philosophy was the belief IDF has a responsibility to set an example about appropriate language to others and is illustrated by the following vignette. The vignette was loosely based on Chaucer's *The Canterbury Tales* (Chaucer 1342–1400)

Once upon-a-time, a group of people with diabetes set out on a pilgrimage to their weekly Diabetes Outpatient Clinic. For some, the journey was long and fraught with fear. For others it was a chore, an obligation to be endured, and for others it was a social occasion.

There were many hurdles to overcome along the way such as finding a car park, being seen on time, and having a hypo in the clinic.

In the clinic waiting area the pilgrims sat with other people with diabetes in hard plastic chairs waiting to see the doctor, diabetes educator, podiatrist or dietitian: sometimes all four. To pass the time, they began to tell stories.

- How come you're here?
- I've got the diabetes.
- Really! I suffer from it too.
- We're all victims here - I'm waiting for a lecture about diet.
- Ha! I've got a lifestyle disease too—I got it because I eat all the wrong things and don't exercise.
- You mean you're non-compliant?
- What's that?
- You know, it's what they say when you don't do as you're told, you know, test your blood

glucose, eat good food, stop smoking, that sort of thing.

- They said my sugars are bad and if I don't do something about it I could go blind.
- That's true, I saw in the paper diabetes is a killer disease.
- Really?
- Yeah; The Bulletin said it is a 'silent plague.' That makes me feel pretty bad, I tell you.
- I thought I was a diabetic: now you're saying I might have a plague?
- Yeah, they call it all sorts of things—depends who you see.
- I just follow their orders. If they suit me. I can't get my head around all those lists of things they tell me to do.
- Don't try to get your head around it. Just do it. Then you'll be all right—compliant and all that stuff.

The vignette illustrates the powerful impact language has on what people do, think, feel and say, but people's actions and conversations with health professionals may not reflect how they feel. Most of the speakers in the vignette used a 'diabetes dialect or code,' for example, 'diabetic,' 'sufferer,' 'plague,' and 'lifestyle disease.' People's comments about the words are shown in Table 1.

TABLE 1:

Column one shows words commonly used in the literature to describe or refer to people with diabetes. Column 2 shows people with diabetes' comments about words they found hurtful, made them angry or felt did not reflect their individuality or ability to make rational decisions. People with diabetes' comments were derived from the literature and interviews and informal discussion about 'diabetes language' with people with diabetes.

HEALTH PROFESSIONAL LITERATURE	PEOPLE WITH DIABETES' COMMENTS ABOUT THESE WORDS
Diabetic	<p><i>I am not a noun</i></p> <p><i>It does not usually worry me but it depends on how it is said.</i></p>
Patient	<p><i>I am only a patient if I am in hospital.</i></p> <p><i>I do not live in a hospital</i></p>
Sufferer	<p><i>I do not suffer from diabetes. I have it and sometimes it is a nuisance but I am not suffering.</i></p>
Victim	
Non-compliant	<p><i>That is a simplistic label for a complex set of decisions and behaviours I make about whether I blindly follow what other people say or not. If I choose not to follow I have my reasons.</i></p> <p><i>Everybody is non-compliant about something some time, even doctors and nurses. Lots of things can make it hard to do things and that does not make me non-compliant. You need to understand why I can't or don't do things not label me.</i></p>
Non-adherent	<p><i>Just another way of saying non-compliant and I am not sure it is much better.</i></p> <p><i>I don't really know what it means. Sounds like another label.</i></p>
Test	<p><i>Tests, investigations, depends on how the word is used. I test my blood glucose but my brother says he measures his.</i></p>
Performing (with respect to diabetes self-care and sexual activities)	<p><i>I do it [diabetes self care] for myself not to amuse other people.</i></p>

Control	<i>Depends on how the word is used and many things can affect control if you are talking about blood glucose and other things.</i>
	<i>I am self-controlled and I manage my diabetes so I don't have problems like blindness.</i>
Normal and abnormal	<i>What exactly is normal? I know what is normal for me but that is not normal for you because we are different. So I do not know what abnormal is except for me.</i>
	<i>I guess if you mean what it is like for the average person then you can use those terms but who is an average person. I could never really figure that out.</i>
Conform	<i>Conform to what? Sounds like I have to do it and I have no say in it and I am naughty if I don't [conform].</i>
	<i>I have a care plan, and that is better because conform sounds like I have to do what somebody else says no matter if it suits me or not. It means I have no say in the matter</i>
Regime	<i>Regime is like in the army and we know what a lot of armies are like. I do not like the word for my diabetes care.</i>
	<i>I think that is a doctor word, I have some goals and a plan , is that a regimen?</i>
Fail/failed	<i>I may not always get it right but I do not think that means I failed.</i>

These words are all inherently negative and can generate a great deal of stress. When these words are used repeatedly to describe people, they become a definition of an individual, in this case a person with diabetes (Department of Communities, Child Safety and Disability Services (DCCSFS) 2012). Such 'definitions' can ultimately affect the way people with diabetes see themselves and are seen by

others, usually as being 'different' (DCCSFS 2012). Habitually using such words (habitual vocabulary) affects what people, including the user, experience.



LANGUAGE CODES

Languages are made up of collections of words, and are used to communicate within and between groups and individuals. Words can facilitate or hinder communication and create or modify feelings and affect physical and mental wellbeing (Bernstein 1971; Littlejohn 2002). The language people use in everyday conversations influences assumptions about particular social groups. In addition, 'everyday' language differs from academic English such as the language used in professional publications: but even academic language differs among the various health professional disciplines.

The way relationships are established within social groups influences the way the group and individuals in the group use language, the type of speech and words they use and how they use them (Bernstein 2002). Significantly, language is a code. Littlejohn (2002) stated 'people learn their place in the world by virtue of the language codes they employ.' That is, the language people use signifies their social identity.

Bernstein (1971 and 2002) defined language codes as elaborated codes and restricted codes. Restricted code does not refer to a 'limited' vocabulary, and elaborated code does not refer to better or more eloquent language. The distinction between the two

codes lies in when and how the language codes are used. For example, elaborated code language describes everything in detail so the information can stand on its own and the majority of people can understand it. Elaborated language codes are important when sharing information with people who do not have a shared background (Atherton 2002). An example where an elaborated language code is appropriate is a diabetes education program for a person newly diagnosed with diabetes.

Restricted language codes are used in everyday conversation when groups have a shared background and a great deal of taken-for-granted knowledge. Restricted codes enable a large amount of information to be conveyed in a few words (verbal shorthand). Each word is linked to a complex set of associations that the hearer needs to know to be able to understand the code. Restricted codes create a sense of inclusiveness (Atherton 2002).

However, restricted codes can also be exclusive if people do not understand the code, which might occur between different cultural groups and people who speak different languages, and even those who speak the same language. An example of restricted code is 'academic language' such as the language academics use in peer-reviewed publications in health professional journals. Another example is the language the people with diabetes used in the vignette on page 5. The vignette also highlights the fact that, although 'diabetes'

might actually be a restricted code (or a dialect!) in its own right, the actual language

can be negative, discriminatory and derogatory and mean different things to different people.

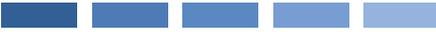
DIABETES DIALECT

Appropriate language codes need to be employed in particular circumstances. 'Diabetes' is a complex language, and like all languages, is constantly evolving (Dunning 2013 P 81). Health professionals frequently use restricted diabetes language code because they have a great deal of information about diabetes and understand the meaning they place on the words they use. However, people with diabetes may not have the same level of knowledge and may not understand the complex associations inherent in words like 'diabetes.' Some people with diabetes learn the restricted diabetes code or dialect over time, as the vignette shows, but they often find the language hurtful, exclusionary and derogatory (table 1).

In addition, the 'diabetes' dialects contains biochemical words rather than the psychological

and social words most people with diabetes use, which can lead to a mismatch between what the health professional says, writes or understands and what the person with diabetes wants to know or understands (Schreeres 2008).

Significantly, although all words have a meaning, and often more than one meaning, people apply their own meanings to words, which means words can mean different things to different people and in different contexts (Choat 2013). Therefore, not every person with diabetes will be distressed if they are called 'a diabetic,' and as the vignette shows, often use the label when referring to themselves: for example 'I am a diabetic' rather than 'I have diabetes.' In addition, other words can be used to modify word meanings, which is why it is essential to clearly define what words mean in conversation and in written information, including research papers.



LANGUAGE STRUCTURE

The structure of different languages varies. Some languages are gendered: that is a gender is attached to nouns. Gender pervasively affects thinking and consequently also affects the way people who speak gendered languages react to nouns designated as a male noun or a female noun (Phillips & Boroditsky 2003). English is not a gendered language. Likewise, some languages like English are futured. Research shows people who speak non-futured languages such as Chinese are more likely to save money than people who speak futured languages (Boroditsky 2001). Boroditsky's research has implications for the way preventative health and risk messages are communicated in specific cultural groups.



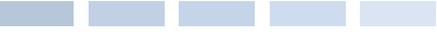
Language can be phrased as a directive, a request or as options to consider. Each type of phrase affects the way individuals respond to the information. In a broad context language affects the way people:

- perceive and remember and recall events;
- make decisions about cause and effect;
- understand verbal and written information;
- feel and experience emotion;
- understand risk and choose to take or avoid risks;
- feel and think about other people (Boroditsky 2003).



SUBLIMINAL MESSAGES

We can detect the power of subliminal messages in the vignette associated with words such as 'plague,' 'victim' and 'sufferer.' Subliminal messaging refers to the embedded content in written information, pictures and electronic media. Advertising experts, movie producers and cult leaders are skilled at



using subliminal messaging to influence people's behaviour and beliefs and often to sell things. Diabetes education can be regarded as a marketing exercise where health professionals try to sell a rather unattractive product to a usually unwilling buyer. Significantly, recipients are not aware they receive or process subliminal messages (Solomon 1994). Some habitual diabetes language such as 'sufferer' and 'victim' can convey subliminal messages to people with

diabetes and the general population and are frequently used by the media.

Subliminal messaging can also occur when

spoken and body languages are not congruent. In this case the listener can become confused, misinterpret one or the other message and/or ignore both.



LANGUAGE AND STRESS

Psychological stress causes changes in proinflammatory cytokine levels such as TNF-alpha, IL-6 (Graham et al. 2006, Wirtz et al. 2007). Chronically high levels of proinflammatory cytokines disrupt homeostasis and are associated with adverse outcomes, reduced immune function and faster progression of age-related diseases, type 2 diabetes, arthritis and frailty in older people (Black 2002; Glaser et al. 2005). Language can engender psychological stress including in relationships. Some research suggests language variables are predictive of health/ill health, especially if language patterns persist over time (Penebaker et al. 1997 and 2003).

Significantly, cognitive processing words (positive language) such as causal reasoning words: understand, because, why and insight words: realise, think, consider, have less impact on inflammatory cytokines and negative mood in conflict situations after controlling for demographic variables, hostility and depression. In addition, cognitive processing words are associated with

increased satisfaction with the conversation (Graham et al. 2006). Graham et al's research suggests productive communication with and about people with diabetes could significantly influence the outcomes of health professional-person with diabetes relationships.

In addition, engagement in a conversation is important and is influenced by factors such as the tone of voice, the emphasis speakers place on words, and body language that accompanies verbal language. These factors in turn influence how verbal messages are sent and received and the impact they have on the listener. Emotion laden language helps people recognise words faster and more accurately, but people do not recall emotion-laden speech as accurately as neutral speech (Schirmer 2012). Women are more sensitive to the emotional elements of language than most men. However, emotion-laden language produces changes in long term memory and influences how words are recognised. Thus, voice, other emotional signals and language affects listeners in the long term.

RECOMMENDATIONS

Aristotle said; *'the appropriateness [of language] is the one thing that makes people believe in the truth of your story'* (Rhetorica).

The following recommendations were developed as a guide to the appropriate written and spoken language to use when speaking about or with people with diabetes and in IDF written and spoken communication. Words to avoid and some suggested alternative words are shown in Table 2. The recommendations encompass:

- communicating with and about people with diabetes;
- writing education materials for people with diabetes and the general public;
- academic writing and other publications for the IDF.

COMMUNICATING WITH AND ABOUT PEOPLE WITH DIABETES

- Reflect on how your habitual diabetes-related vocabulary (words you use all the time), your tone of voice and your body language could affect people with diabetes during a consultation and in the long term;
- Each person is a unique individual. Some people

become distressed by words such as diabetic and non-compliant; others do not. Thus, it is important to listen to the language and words the person uses and try to use these words when conversing with them;

- Observe how the individual reacts to the language you use, not just at the time, but, over time. Use probing and clarifying questions when relevant to gain relevant information but not to imply a judgement;
- Help the individual develop strategies to manage stress and think about how the language you use and the possible subliminal messages you might convey could lead to stress;
- Ensure policies and procedures and education programs reflect appropriate language about diabetes generally, and about people with diabetes in particular;
- Monitor language use and impact as part of routine service quality improvement evaluation/audit processes e.g. record the number of times potentially inappropriate words are used during conversations with colleagues and/or with people with diabetes and note changes over time.

WRITING EDUCATION MATERIALS FOR PEOPLE WITH DIABETES AND THE GENERAL POPULATION

- Include people with diabetes when planning

education programs and services to ensure language and messages are appropriate to the target group;

- Be aware that many people with diabetes who take a leading role in consumer organisations and sit on consumer reference groups are often highly educated and articulate and their views and language may not be appropriate for your target audience;
- Assess written information and education materials developed for people with diabetes to ensure the language is appropriate and is at a suitable literacy level for the intended readers. Ideally, people with diabetes will be involved in such assessments. The feedback should be used to revise the material if necessary and then retest the material;
- Consider the educational content and the language likely to most effectively convey the content or key messages. The language, and consequently the information/education program, is only useful if the target audience understands it;
- Consider the way the information is structured and whether it flows as a cohesive story e.g. it is grammatical, uses active language, which is much easier to read and is less ambiguous. In addition, consider other important issues that affect the readability of the information such as the design and layout of the information, colour contrast, font size and font type;
- Find out how the target audience learns and use the information to plan education strategies for individuals and for groups;

- Ensure illustrations relate to the text and are used in a relevant context. Pictures of disembodied eyes and kidneys are not useful for most people with diabetes because most people with diabetes do not have the relevant anatomical knowledge to place the pictures in context;
- Evaluate written education materials and questionnaires before they are used and then at regular intervals as part of continuous quality improvement and because language is dynamic and changes over time, sometimes rapidly; e.g.
 - > Focus-testing with key informant groups;
 - > Cognitive debriefing to establish face and content validity;
 - > Suitability Assessment Method (SAM);
 - > CLOZE;
 - > Simplified Measure of Gobbledygook (SMOG);
 - > Consider recommendations such as those of The International Association of Patient Organisations (IAPO).

ACADEMIC WRITING AND PUBLICATIONS ESPECIALLY FOR THE IDF

- Consider the recommendations in the preceding two sections;
- Avoid using words that contribute to the inappropriate habitual language associated with diabetes. It is possible to use appropriate language and comply with journal author guidelines.

TABLE 2:

Column one suggests words that should be avoided where possible and column two suggests some alternative word choices, especially when communicating with people with diabetes.

WORDS TO AVOID IF POSSIBLE	ALTERNATIVE WORDS
Diabetic	<i>Person with diabetes if referring to an individual, people with diabetes if referring to more than one person with diabetes or a human being/s.</i>
Not everybody is concerned about being referred to as 'a diabetic.' Some people are initially concerned but accept it over time because it is habitual health professional language, which they absorb through subliminal messaging. Others never adjust to being called 'a diabetic.'	
Patient	<i>Person with diabetes unless specifically referring to a person with diabetes in hospital if referring to an individual, people with diabetes if referring to more than one person with diabetes.</i>
Sufferer	<i>Person with diabetes if referring to an individual, people with diabetes if referring to more than one person with diabetes.</i>
Victim	<i>Person with diabetes if referring to an individual, people with diabetes if referring to more than one person with diabetes.</i>
Non-compliant, non-adherent, non-concordant	<i>Having difficulty following your care plan, testing your blood glucose, managing your medicines.</i>
Should or must	<i>What do you think would work for you? Have you considered...?</i>
Test e.g. blood glucose and other investigations	<i>Check, monitor,</i>
Perform/performing (with respect to diabetes self-care and sexual activities)	<i>Undertake, do</i>

Control or poor control referring to blood glucose and other metabolic targets.

Your blood glucose (or other parameters) is within your optimal range OR

Equally good control

You are meeting your blood glucose goals.

Both terms are subjective and are often judgmental

Normal and abnormal

Usual for the person concerned or within the expected range or similar to most other people with /without diabetes

Different from usual and usually has a negative connotation

Conform

Meet your goals

Regime

Care plan (preferably) or regimen

Fail/failed

Not meeting your goals

Shot (insulin injection)

Insulin injection

Is appropriate in some countries but may mean illicit drug use in other countries

Note:

Some people with type 1 diabetes become upset if type 1 and type 2 diabetes are referred to by the general term 'diabetes' or a 'lifestyle disease.' Likewise, lifestyle disease can be disparaging to people with type 2 diabetes because environment and genetic factors also have a role in the development of type2 diabetes.



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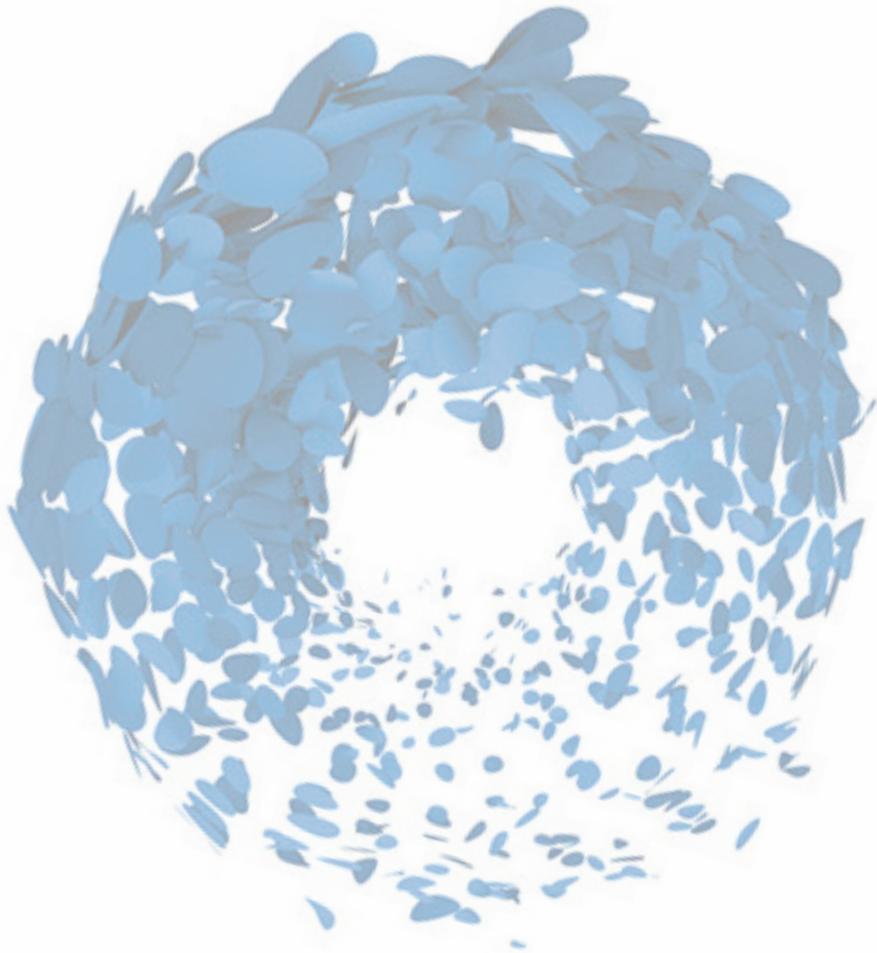
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NOTES

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