Including patients' perspectives in patient information leaflets: A polyocular approach

Antoinette Fage-Butler

Abstract Existing research reveals that patients' perspectives are missing from mandatory patient information leaflets (PILs). At the same time, there is overwhelming consensus that they should be included in this genre, and a corresponding need for potential approaches to tackle this problem. This paper examines the appropriateness of perspectivist theory as a means of conceptualising the underrepresentation of patients' perspectives in PILs. It also offers a framework for a possible solution that draws on polyocular theory, as polyocular approaches can support communication across perspectival asymmetries. The paper contributes theoretically in its innovative use of perspectivist theory in relation to text, and in identifying that the insights of polyocularity could valuably inform a new health communication paradigm, as current health communication paradigms do not fully recognize patients' perspectives. Apart from its theoretical contributions, the paper includes guidelines to support the production of PILs where patients' perspectives are included. The guidelines are informed by practices that have characterised previous polyocular communication events, as well as research into how to maximize patient participation in contexts where various forms of expertise are at play.

Keywords patient information leaflets, patients' perspectives, health communication, perspectivism, polyocularity

1 Introduction

Patient information leaflets (PILs) are legally required to accompany medication in the EU; they contain information about the composition of the medication, contraindications and possible side-effects, as well as instructions on how to take the medication correctly. Despite their potential value to patients, they are considered a 'dysfunctional' genre (Askehave/Zethsen 2008: 171). Many problems have been identified as problematic in PILs:

- poor comprehensibility (Askehave/Zethsen 2000, Cronin/O'Hanlon/O'Connor 2011, Horwitz/Reuther/Andersen 2009),
- poor layout with too small font (Bernardini et al. 2001, Horwitz/Reuther/Andersen 2009), poor communication about risks (Berry 2006, MHRA 2005, Osimani 2010),
- not meeting patients' needs (Consumers' Association 2000, MHRA 2005, Nicolson et al. 2006, Raynor et al. 2007).

The problem that is explored in this paper relates to patients' frustrations that their perspectives are absent from these texts. This shortcoming is documented in research that spans a range of different methodologies and purposes. For example, in their experimental study, Berry et al. (1997: 476) found that what patients wanted from such written information was at odds with what doctors thought they wanted. On that basis, the authors suggest that a balance be struck between biomedical and patients' perspectives in PILs, though they do not explain how this might be achieved. Similarly, in their focus group study, Nicolson et al. (2006) using stakeholder workshops found a mismatch between what patients actually wanted in mandatory PILs, which was consistent with the patient empowerment model of health communication, and the findings of existing literature reviews, meta-analyses and narrative reviews of the role and effectiveness of PILs which reflected themes such as compliance that characterize the patient education discourse. Significantly, Nicolson et al. (2006: 117) recommend that patients should therefore be involved "from the outset, i.e. in the content setting, rather than bringing them in only at the end to assess the readability of written information". In suggesting that patients contribute to determining the content of PILs, Nicolson et al. (2006) anticipate the polyocular approach outlined in this paper. In addition, in their focus group study conducted in Iceland, Björnsdóttir/Almarsdóttir/Traulsen (2009) encountered the public belief that the pharmaceutical industry as a whole needed to consider to a greater extent the needs and perspectives of the patient: participants in the study advocated that pharmaceutical companies should "think about the person who needs the cure, […] perhaps just think about the human, the individual" (Björnsdóttir/Almarsdóttir/Traulsen 2009: 47).

Besides studies that elicit patients' views, a discourse analytical study provided evidence at the textual level of patients' missing perspectives in PILs. Using Foucauldian discourse analysis, Fage-Butler (2011) identified that the subject positions (or discursive "presences") in mandatory PILs relate primarily to expert disciplines such as risk management, pharmacology and biomedicine, with a concomitant neglect of patients' perspectives.

Lastly, the importance of including patients' perspectives is regularly underlined in theoretical papers that outline how improvements could be made to PILs. Like Nicolson et al. (2006), the Medicines and Health Products Regulatory Agency, the British regulatory authority for PILs, recommend that patients be involved in developing the content of PILs in order to ensure that their needs and interests are reflected (MHRA 2005: 28). Grime et al. (2007: 286) identify "[t]he different perspectives of patients and health professionals" as a particular challenge to producers of PILs, whilst van der Waarde (2008: 37) underlines the urgency of addressing this blind spot, asserting that since PILs are intended to provide patients with information, "we must start from the patient's point of view". Raynor/Dickinson (2009: 702), following consultations with information design experts, similarly recommend that producers "put […] [themselves] in the reader's position".

In sum, a review of the literature reveals unequivocal awareness of the problem as well as some suggestions to address it, but there has been a lack of significant focus on theoretical dimensions of patients' perspectives. This refers to what these are, and how they might in practice be identified and included in texts which are currently considered to reflect senders' perspectives only.

It is the purpose of this paper to characterize the problem of the lack of patients' perspectives in PILs by applying perspectivist theory, and to suggest ways of tackling the problem using polyocular theory. Perspectivist theory (Alrøe/Noe 2010, Alrøe/Noe 2011, Giere 2006) provides valuable theoretical purchase on the notion of perspectives, pointing in the direction of how they may be accommodated; it also provides a clear, convincing and philosophically underpinned account of the challenges involved in incorporating more than one perspective. Polyocularity theory (Alrøe/Noe 2011, Noe/Alrøe/Langvad 2005, Noe/Alrøe/Langvad 2008), on the other hand, is employed because of the potential of polyocular communication to create a "multidimensional space of understanding" (Alrøe/Noe 2011: 164) that could accommodate the heterogeneity of different perspectives. The paper has two main outcomes. First, it describes guidelines for polyocular communication which are intended to support the eliciting and sharing of the various stakeholders' perspectives in PILs. Second, it establishes that the perspectival problems evident in PILs are also present in health communication paradigms which influence the discursive resources (language, ideology and values) employed in health texts, suggesting the value of a paradigm shift in health communication theory that is informed by the insights of perspectivism and polyocularity.

2 Health communication paradigms and perspective

The missing perspectives of patients in PILs have been empirically identified using focus groups and discourse analysis. However, the marginalization of patients' perspectives in health texts is also evident in the various health communication paradigms that frame the role and status of health professionals and patients as well as the aims of medicine and communication. This is, of course, not to assume that the absence of patients' perspectives in PILs is exclusively a paradigmatic matter – there are always contextual factors that impact on texts (Sarangi/Candlin 2011, van Dijk 2009, Widdowson 2004). It is just that as text and talk are inevitably shaped by paradigmatic understandings, suppositions and values (Dixon-Woods 2001, Thorne/Nyhlin/Paterson 2000), it is important to examine the assumptions of existing health communication paradigms. Indeed, these paradigms also rely on discourse for their reproduction. Drawing on overviews of the main doctor-patient health communication paradigms by Lupton (2003), Pollock (2005) and Beisecker/Beisecker (1993), the biomedical paradigm, patient centeredness, patient education, and patient empowerment are now scrutinized in relation to their respective conceptualizations of patients' perspectives.

Scientific progress during the Enlightenment led to the biomedical approach to medicine. In this paradigm, the doctor's perspective is primary, and patients' perspectives are broadly considered to be irrelevant in the face of biomedical expertise. The patient – the object of the "clinical gaze" (Foucault 1973) – is diagnosed on the basis of biological symptoms. Focus is on clinical disease rather than experienced illness. A power asymmetry prevails: a powerful, knowledgeable doctor and a passive, lay patient (Mead/Bower 2000). In the patient centeredness paradigm, by contrast, there is greater emphasis on meeting the needs of the patient, as Balint (1969: 269), who introduced the idea of patient centeredness, asserted: "the patient, in fact, has to be understood as a unique human being". However, it needs to be remembered that patient centeredness accommodates and facilitates the aims of biomedicine. Patient centeredness, whilst being applauded as a morally sound option (Duggan et al. 2006), has been promoted as a means of improving diagnostic procedures. Patient-centered communication can help the doctor to understand the condition better (Balint 1969, Engel 1977), and in its orientation to the patient, it can make doctor-patient communication more cordial (Stewart 1995, Stewart et al. 2000), leading to less positive associations of patient centeredness with sugar-coating (Fage-Butler 2011: 113). Step et al. (2009: 370) and McCormick (1996: 667) also observe that the structural imbalance of power and knowledge in the doctor-patient relationship renders "therapeutic alliance" (Mead/Bower 2000), one of the aims of patient centeredness, impossible. In the patient education paradigm, by contrast, the enhancement of patients' understanding as opposed to promoting their perspectives is central. The communicative objective is that patients, who are assumed to be lay, improve their understanding of biomedical information to maximize their health benefits (Hoving et al. 2010). Finally, the patient empowerment paradigm for doctor-patient communication has an emancipatory objective: empowerment lies in patients' awareness of their options, but in order to acquire such, they rely on medical expertise. The paradox at the heart of patient empowerment is that patients are typically "empowered" by medical experts, emphasizing their subordinate position (Askehave/Zethsen 2010, Burke 2008, McGregor 2006).

The findings described so far reveal that the perspectival problems that are documented in PILs are also apparent at a deeper "macro" paradigmatic level. In each of the paradigms considered, it is evident that patients' perspectives either have little significance in the communicative situation where professional health expertise is involved, or they are primarily deemed relevant in relation to biomedical objectives rather than having value *per se*. The lack of a health communication paradigm that fully recognizes patients' perspectives in this situation is problematic: it normalizes the marginalization of patients' perspectives, perpetuating the problem. Moreover, such paradigms are out of step with more recent understandings of the patient as being equipped with valuable and unique expertise on the basis of their experiences with their condition (Department of Health 2001, Hartzler/Pratt 2011, Petersen 2006, Shaw/Baker 2004). Significantly, the sharing of patients' experience-driven expertise with biomedical experts is considered to be hampered by a lack of strategic knowledge that could "facilitate a structural participation" (Caron-Flinterman/Broerse/Bunders 2005: 2582), whilst Kerr/Cunningham/Amos (1998: 57) argue for the need for different power structures to facilitate dialogue between lay experts and scientific experts. This paper focuses precisely on the challenges involved in managing such complex dialogues across perspectival asymmetries. While not going as far as developing a new health communication paradigm, it contributes by identifying perspectival blind spots in existing paradigms, and it indicates the possibility of countering the current mono-perspectival approach in mandatory PILs using polyocular theory.

3 Perspectivism

Perspectivism is employed in this paper to provide theoretical leverage on the absence of patients' perspectives from PILs. As a philosophical approach, it refers back to Leibniz and Nietzsche (Giere 2006: 3). Leibnizian perspectivism problematizes the relationship between individuals and the world: not only do subjects have to rely on their own individual perceptions (Kleist 2000: 95), but more radically, subjects are constituted by their point of view (Smith 2005: 133). In Leibnizian perspectivism, only God has access to what Kant would call "noumena", or objects that exist independently of cognition or the senses (Halbmayer 2012: 10). Nietzsche, on the other hand, rejected the idea of both an objective reality and a God-like standpoint from which everything could be surveyed, or what he metaphorically describes as "an eye turned in no direction at all" (Nietzsche 1994 [1887]: 92). Given that only kaleidoscopic, personal versions of reality exist and perspective cannot be eliminated, Nietzsche argued that interpretations should be shared in order to enhance our understandings of an object, anticipating related arguments in polyocular theory (Nietzsche 1994 [1887]: 92).

Giere (2006) has more recently developed perspectivist theory and applied it to modern-day academic (natural) science. In perspectival science, researchers are locked within disciplinary perspectives, recalling Kuhn's (1970 [1962]) incommensurable paradigms. Giere's perspectivism challenges the ontological position generally attributed to science, namely, objective realism; instead, scientists' claims to truth are contingent, permitting weaker epistemological statements like: "According to this highly confirmed theory (or reliable instrument), the world seems to be roughly such and such" (Giere 2006: 6). Because the object of scientific analysis is fully contingent on the ways in which it can be known as there are "epistemological conditions for observation and the built-in values and norms that apply in the perspective where it is grounded" (Alrøe/Noe 2011: 156), perspectivism assumes the primacy of epistemology over ontology, where how we know determines what we know. Alrøe/Noe (2011: 155) summarize the core aspects of perspectivism as follows:

> There is no outside perspective on the world. All knowledge comes from a certain perspective. All learning happens in concrete perspectives on the world, which are part of the world and which can themselves be made objects of observation.

Fundamental to perspectivism, thus, is the idea that knowledge is not origin-innocent, but is always associated with a locus of observation, which for Alrøe and Noe can be disciplinary, professional and/or personal. What is "true" can only be considered true according to the "norms and values that apply in the perspective in which it is grounded" (Alrøe/Kristensen 2002, Alrøe/Noe 2011: 156). Moreover, Alrøe/Noe (2011: 155) extend Giere's view of scientific perspectivism to include the natural, social and human sciences. Significantly, they conceptualize the general public as stakeholders whose perspectives are also incommensurable with other perspectives, hence the appropriateness of perspectivism to the present study which is concerned with the inclusion of patients' perspectives.

Perspectivist theory usefully helps to account for a number of the obdurate challenges associated with interperspectival communication. First of all, stakeholders may believe they are speaking about the same object when it is, in fact, a "dynamic object" in the Peircean sense (Alrøe/Noe 2011: 158), made slippery by the fact that it is framed by different perspectives in very different ways. Secondly, the power differential between respective perspectives also problematizes interperspectival communication, as the disciplinary perspective that is hegemonic will tend to override all others (Alrøe/Noe 2010: 527, Alrøe/Noe 2011: 154).

4 Polyocularity

Polyocularity has been proposed as a way of dealing with communication challenges of a perspectival nature (Alrøe/Noe 2010, Alrøe/Noe 2011, Noe/Alrøe/Langvad 2005, Noe/Alrøe/Langvad 2008). How polyocularity can be considered to provide solutions to the communication problems associated with perspectivism is perhaps best discussed in relation to Alrøe/Noe's (2011: 161) table (see table 1 below). It characterizes types of knowledge, types of disagreement and types of learning in relation to perspectivism.

Table 1: First order vs. second order perspectives (derived from Alrøe/Noe 2011: 161)

		Type of knowledge and expertise	**Type of disagreement**	**Type of system learning process**
1.	**Between perspectives (of first order)**	Acontextual knowledge, interactional expertise	Unconnected 'blind' disagreement, Communication failure	'Learning the language', Hegemony, Boundary-work
2.	**In a second order perspective**	Contextualised knowledge, Reflexive expertise	Perspectival disagreement	Second-order polyocular communication

As can be seen in table 1, Alrøe/Noe (2011) employ Luhmann's (1993) distinction between "first order observation" and "second order observation" in their discussions of polyocularity. The former has to do with employing discursive resources (primarily language) and not questioning discursive distinctions or categories, but simply applying those distinctions. It generally characterizes what happens when people engage in acts of communication. Second order observation, by contrast, is an analytical stance characterized by awareness that the distinctions that apply in communication between perspectives are merely distinctions and that other distinctions are possible. As with Derrida's (1982) concept of *différance*, second order observation is ever-alert to selectivity and blind spots. Its aim is to de-naturalize distinctions that have been taken for granted (Andersen 2003: 65), instead considering how such distinctions are produced. As second order observation involves reflection, there needs to be a third party observing the interactants engaging in first order observation, as they can identify what "first order observers" demarcate, and analyse the basis for such demarcations, whether they are considered ideological, disciplinary or discursive.

Returning to table 1, where *interperspectival first-order communication* takes place without perspectival mediation (see row 1), the type of disagreement associated with this kind of communication recalls the problems that have been identified in PILs – patients' sense of communication failure or breakdown, blind-spots and disagreement about priorities. In a sense, this is inevitable in first order communication because, according to perspectivist theory, "each observational perspective has its own phenomenal world – its own representation of the world entailed in theories, models, concepts, classification and examples" (Alrøe/Noe 2011: 159) which has the effect of blinkering observers to perspectives other than their own, despite good intentions to be open to other perspectives. Thus, doctors and patients, for example, may try to "learn the language" (see table 1) of each other in an attempt to address the problems of first order communication. Patients can approach the language of biomedicine and doctors adopt a more patient-centered style. However, following the logic of perspectivist theory, the hegemonic perspectives of biomedicine will most likely prevail. This is all the more problematic given the current lack of a health communication paradigm that fully recognizes the value and integrity of patients' perspectives, as outlined in Section 2.

Row 2 of table 1, on the other hand, indicates Alrøe/Noe's (2010: 529) response to "the difficulties of communicating directly across different perspectives". Given that perspectives, like Kuhnian paradigms, are "incommensurable" (Kuhn 1970 [1962]), the solution that Alrøe and Noe propose is not to merge or overlap perspectives. Instead, they start from recognition of the various perspectives' unavoidable, existing heterogeneity. They introduce the idea of polyocularity to capture the idea that second order observation involves the spanning of different perspectives. Polyocularity was first coined by Maruyama (1974, 2004) who developed the concept of polyocularity for cross-cultural and organizational studies. Polyocularity can be represented graphically as shown in figure 1:

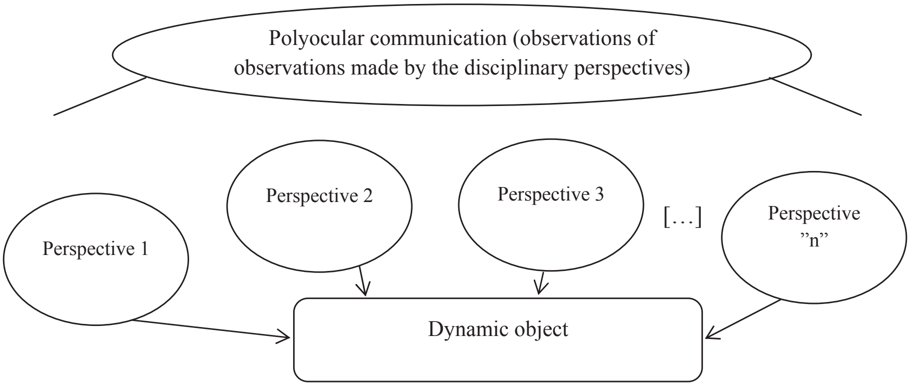

Figure 1: Overview of polyocular communication, involving second order perspectives on first order perspectives of a dynamic object – a schematic diagram based on a figure in Alrøe/Noe (2011: 163).

The promise of a second-order polyocular approach, Alrøe and Noe contend, is that it "can potentially transcend the incommensurability of perspectives that are blind to each other" (Alrøe/Noe 2011: 160–161). The outcome of such communication is thus the possible unfolding of "a multidimensional space of understanding" (Alrøe/Noe 2011: 164) – a space which accommodates more than one perspective.

Extra human and financial resources are required to facilitate second order polyocular communication because, as Alrøe/Noe (2011: 163) point out, it is very difficult to undertake first and second order observation as parallel activities: "The specialized disciplines are generally not able to both reproduce and refine their own perspective and carry out second order observations of the different perspectives (including their own) that are employed in cross-disciplinary research." The team which was assembled to provide second order perspectives could be a group that consisted of stakeholders from the various perspectives. Such a taskforce would:

> 1. illuminate the involved perspectives and their conditions for observation, communication and learning, in order to 2. enable a contextualised communication of observations and analyses, which exposes how they are influenced by their perspectival and cognitive context and thus help overcome perspectival knowledge asymmetries, and thereby 3. provide for a polyocular communication of the research results. (Alrøe/Noe 2011: 164)

The guidelines which are presented in Section 5 consider in more detail how these three aspects could support the identification of patients' perspectives so that they could be included in mandatory PILs. In using a polyocular approach to secure the objective of *texts* including the perspectives of the relevant stakeholders, this paper builds on as well as departs from previous polyocularity research which has employed polyocular theory to improve communication in live situations. The present focus on using polyocularity to secure the inclusion of the perspectives of the relevant stakeholders in texts recalls Bakhtin's (1984) theory of textual polyphony which postulates that various voices exist in texts and that they relate to "experiences of […] actual people as sources of meaning and expressivity" (Belova/King/Sliwa 2008:

496); see also Fløttum (2010) and Fløttum/Dahl (2011). Another notable point of comparison between the polyocular approach adopted in this paper and Bakhtinian theory is that polyocularity has been proposed as a means of managing the problem of the mutual impenetrability of perspectives, and Bakhtin (1986: 7) asserted that, to maximize understanding, an observer needs to be "located outside the object of his or her creative understanding – in time, in space, in culture", recalling the distancing effects of second order observation.

5 Employing polyocularity to improve PILs

Since there is no "blueprint" to carry out second order polyocular observation and communication (Noe/Alrøe/Langvad 2008: 12), the issue of how one might employ a polyocular approach for the specific instance of PILs will be addressed in this section. Thus the main intention is to contribute theoretically-anchored guidelines that could support the inclusion of patients' perspectives in PILs in future studies. A pilot study would be very valuable to determine how best to operationalize these guidelines for specific polyocular sessions on PILs.

The guidelines were developed from two main theoretical sources: statements on how to conduct generic polyocularity (second order observation and communication), described in the publications by Alrøe, Noe and colleagues (Alrøe/Noe 2010, Alrøe/Noe 2011, Noe/Alrøe/Langvad 2005, Noe/Alrøe/Langvad 2008), and theoretical insights into how to increase patient participation in a health setting (Jauffrey-Raustide 2009, Kerr/Cunningham/Amos 1998, Schicktanz/Schweda/Wynne 2012). In this way, previous experiences with polyocular communication are combined with insights that are sensitive to the inclusion of patients' perspectives. Interestingly, there were many instances of similarities in the two theoretical approaches which appear to have evolved more or less independently. For example, Schicktanz/Schweda/Wynne (2012: 137) espouse stakeholder sessions where patients get the opportunity to remind powerful institutions of responsibilities which they may be reneging, and proponents of the polyocular approach are similarly alert to the negative impact of disciplinary hegemony.

What follows is an overview of aspects of a polyocular communication session that could support the objective of identifying how PILs could become multi-perspectival. What is offered is not a method *per se*, but rather methodologically significant focus-points for polyocular communication in a health setting which are relevant to the specific instance of how to improve PILs:

1. *Setting: A multi-disciplinary focus-group format*
   Both polyocularity and health-related research suggest similar forums for the exchange of first order observations. Noe/Alrøe/Langvad (2008: 9) espouse a multidisciplinary study, and Kerr/Cunningham/Amos (1998: 58) argue for health-related focus groups where the various stakeholders are included, as they found that this arrangement supported the eliciting of patients' perspectives: "Our research experience would suggest that focus groups, based on respect for all the participants' views, are a better model for public consultation than either the medical encounter, where lay people's expertise is often denigrated, or formal public debates, where deferment to scientific expertise is likely."

2. *Identifying the stakeholders*
   Setting up a polyocular session also involves identifying and assembling the relevant stakeholders (Alrøe/Noe 2010: 531). A minimal approach in the case of PILs would be to

assemble groups of patients and representatives from pharmaceutical companies who produce PILs. Schicktanz/Schweda/Wynne (2012: 314), however, advocate a broader approach to patient participation. They suggest the following categories with which to identify an "affected person": those who are affected directly and indirectly, and those who are affected actually, prospectively (at some point in the future) and potentially (at any point) (Schicktanz/Schweda/Wynne 2012: 135). In their bioethical study, for example, Schicktanz/Schweda/Wynne (2012: 136) identify the following public stakeholders: patients, representatives of patient organizations or members of disability groups. Relevant stakeholders for a broader stakeholder involvement for PILs would need to be established through a careful stakeholder analysis. Whether the minimal or broad approach is used, it would be most equitable to have an equal number of representatives from the producing and receiving end.

3. *Identifying the polyocular team*
   From the various stakeholders and disciplinary perspectives, members would need to be found that could act as second order polyocular observers and communicators. Their task would be to ensure that the various perspectives were identified, that communication was supported, and that outcomes were generated (Alrøe/Noe 2011: 164). Again, it would be beneficial to include an equal number of individuals taken from amongst the stakeholders that represent the receivers of PILs and those that represent the producers of PILs.

4. *Identifying a session leader*
   A session leader should be appointed whose main task was to ensure that hegemonic perspectives were kept in check. Related to this point, Noe et al. (2005: 15) have asserted that it is important in second order polyocular communication to establish a rule outlining the "kind of arguments that are legal in multidisciplinary communication". If possible, a perspectivally "other" person would be found for the role – this could, for instance, be a researcher.

5. *Agreement as to the object*
   There needs to be general understanding of the object being discussed, and of the nature of the problem. This is not straightforward as the object (here, the mandatory PIL) is dynamic (cf. figure 1) as disciplines, for example, define objects narrowly to meet their needs, whilst stakeholders such as patients have a more experiential approach to the object. However, identifying the complex and slippery quality of the object and the question that pertains to the object from the various perspectives using second order observation is central to the practice of a polyocular communication.

6. *The tasks of the polyocular team: Eliciting perspectives*
   The polyocular team engaging in second order observation would pay attention to the meanings, values and interests of the various perspectival groups contributing to a polyocular session on PILs. This is mirrored in comments made by Schicktanz/Schweda/Wynne (2012: 133) who state that there are three areas where it is important that patients' views are heard: problem identification, examination of empirical premises and application of normative directives. Identifying perspectival arguments should be informed by an understanding of the nature of the various perspectives. As described in Section 3, perspec-

tive in the polyocular approach of Alrøe, Noe and colleagues is primarily associated with knowledge. In the case of patients, Jauffrey-Roustide (2009: 159) describes patients' expertise more broadly as incorporating "practical, emotional and subject knowledge". The polyocular team would need to be aware of the meaning of perspectives for the perspectival groups in question. The analytical orientation of Luhmannian second order observations proposed by Alrøe and Noe is also echoed in Schicktanz/Schweda/Wynne (2012: 136) who recommend that the attitudes and arguments of the various stakeholders be analyzed and interpreted qualitatively. The intention behind identifying the nature of the various perspectives and communicating these to the various perspectival groups is that it should lead to an enrichment of discussions and more perspectivally-aware conclusions. This is particularly important when perspectives are missing as in the case of PILs. Through greater awareness of the various perspectives, a perspectivally heterogeneous platform for inter-perspectival communication could be achieved. This has the great benefit of avoiding the lop-sidedness of forums that are intended to generate consensus rather than respect heterogeneity (Alrøe/Noe 2010: 528). The intended outcome, in other words, is improved understanding of the various perspectives which should be represented in PILs, leading to insights that could both inform and transform the practice of writing PILs.

6 Discussion and conclusion

This paper set out to explore the vexed and on-going problem of the absence of patients' perspectives in mandatory PILs, making a number of theoretical and practical contributions.

First, it contributes to improved theoretical understandings not only of the problem of patients' missing perspectives in PILs but also why the problem seems so intractable, despite numerous attempts to improve this genre, e.g. changes in legislation, regulatory initiatives and on-going research (Fage-Butler 2011). Moreover, the paper contributes by extending the application of polyocular theory. So far, perspectivist and polyocular theories have only been used in the live interactive setting to support the identification of stakeholders' perspectives. Considering the application of these theories to support the production of texts that better meet receivers' needs and expectations is innovative. Using the aspects presented in Section 5 as a basis for the construction of a polyocular session could help shed light on how PILs could better reflect patients' perspectives. Greater awareness of how to identify and include patients' perspectives could vastly improve this genre which by every account is failing its target audience.

Using perspectivist arguments, this paper has also shown that lacunae of a perspectival nature are evident in the health communication paradigms that shape communicative practice. A new paradigm of health communication that fully recognises the integrity and value of patients' perspectives would clearly be very valuable. Here polyocular theory could make significant contributions. Polyocularity could also support the practice of health communication more concretely. Whilst a polyocular approach would be difficult to set up in the day-to-day reality of a clinic because of the need for extra resources, a polyocular approach could certainly be advantageous in other settings, such as medical training sessions, initiatives to improve various health texts, and when identifying patients' perspectives on relevant issues (such as new policies, initiatives or risks), cf. Kerr/Cunningham/Amos (1998) and Schicktanz/Schweda/Wynne (2012).

The limitations of the paper point in the direction of further studies. As mentioned in Section 5, the approach developed in this paper needs to be developed further. Given the novelty of polyocularity sessions in general and the fact that the proposal to extend its application to text is new, a pilot study could help make necessary refinements.

There are also a number of aspects that need further exploration. First, patients themselves have generalized their own perspective, identifying it as missing from PILs. However, it may prove challenging to move from the many individual patient perspectives which can be identified in a polyocular session towards producing a generic perspective for patients, which is needed for PILs, at least in their present form. As patients' perspectives have personal, emotional and cultural aspects, they can hardly be entirely generic. A polyocular approach could perhaps therefore best suit the identification of the perspectives of smaller, more specific target audiences for PILs – such as the elderly, if a medication mainly treats elderly patients, or a patient group such as diabetics. A second issue that could be explored relates to the frequency with which the understandings of patients' perspectives are updated, as perspectives will be dynamic. Third, there is the issue of the nature of perspective. Patients' perspectives have a compound quality incorporating experience, scientific knowledge, and emotion (cf. Jauffrey-Ronstide 2009: 159), but it would be valuable to investigate this further, particularly to investigate how perspectives might translate for the medium of text. A fourth question is methodological in nature: how to identify perspectives in texts. This is an area where critical genre analysis (Bhatia 2010, Bhatia 2012) could make valuable contributions, as Foucauldian discourse analysis can identify the discourses and related subject positions in genres (cf. Fage-Butler 2011). Finally, an implicit and rather underplayed element of perspectivism is its ethical quality. Perspectivism and polyocularity clearly address an ethical problem, namely, the exclusion of "voices, experiences and positions" (Schicktanz/Schweda/Wynne 2012: 137), and it would be very valuable to gain broader understandings of polyocularity as an ethical endeavour.

Overall, there is a need for new approaches in health communication practice and theory where the patient moves from being an object to having subject status (Schicktanz/Schweda/Wynne 2012), or in perspectivist terms, where patients' *perspectives* achieve subject status, rather than being overlooked. Neglecting this issue is problematic, as Noe/Alrøe/Langvad (2008: 5) warn: "It is not a question of more or less sympathetic approaches; the hegemonic position of one perspective always violates other perspectives." A dialogue-based approach, such as that advocated by Olesen (2004, 2012) as an alternative to patient centeredness, should be rooted in an awareness of the incommensurability of perspectives – that one perspective fundamentally constitutes a "black box" for the other.

Polyocularity has been used in this paper not only because it addresses the issue of incommensurability, but also because it holds the tantalizing prospect of patients and other relevant institutional players and experts having an equal standing where they can share their differing perspectives (Schicktanz/Schweda/Wynne 2012, Tuckett et al. 1985). This could transform texts like PILs. If insights into patients' perspectives derived from polyocular communication approaches point to the need for a change in the legislation for mandatory PILs, then that step should also be taken.

References

Alrøe, Hugo F./Kristensen, Erik S. (2002): "Towards a Systemic Research Methodology in Agriculture: Rethinking the Role of Values in Science." *Agriculture and Human Values* 19.1: 3–23.

Alrøe, Hugo F./Noe, Egon (2010): Multiperspectival Science and Stakeholder Involvement: Beyond Transdisciplinary Integration and Consensus. *9th European IFSA Symposium. WS 1.5 – Transdisciplinarity as a Framework for Integrating Science and Stakeholders' Perspectives into Development Processes,* Vienna: 527–533.

Alrøe, Hugo F./Noe, Egon (2011): "The Paradox of Scientific Expertise: A Perspectivist Approach to Knowledge Asymmetries." *Fachsprache. International Journal of Specialized Communication* 33.3–4: 152–167.

Andersen, Niels Åkerstrøm (2003): *Discursive Analytical Strategies: Understanding Foucault, Koselleck, Laclau, Luhmann*. Bristol: The Policy Press.

Askehave, Inger/Zethsen, Karen Korning (2000): *The Patient Package Insert of the Future: Report for the Danish Ministry of Health*. Aarhus: Aarhus School of Business.

Askehave, Inger/Zethsen, Karen Korning (2008): "Mandatory Genres: The Case of European Public Assessment Report (EPAR) Summaries." *Text & Talk* 28.2: 167–192.

Askehave, Inger/Zethsen, Karen Korning (2010): "'Check it out' – The Construction of Patient Empowerment in Health Promotion Leaflets." *English for Academic and Professional Purposes.* Eds. Immaculada Fortanet-Gómez/Juan Carlos Palmer-Silveira/Miguel F. Ruiz-Garrido. Amsterdam: Rodopi. 105–120.

Bakhtin, Mikhail (1986): *Speech Genres and Other Late Essays* (Vern W. McGee Trans.). Austin: University of Texas Press.

Bakhtin, Mikhail Mikhailovich (1984): *Problems of Dostoevsky's Poetics* (Caryl Emerson Trans.). Minneapolis: University of Minnesota Press.

Balint, Enid (1969): "The Possibilities of Patient-Centered Medicine." *Journal of the Royal College of General Practitioners* 17.82: 269–276.

Beisecker, Analee E./Beisecker, Thomas D. (1993): "Using Metaphors to Characterize Doctor-Patient Relationships: Paternalism versus Consumerism." *Health Communication* 5.1: 41–58.

Belova, Olga/King, Ian/Sliwa, Martyna (2008): "Polyphony and Organizational Studies: Mikhail Bakhtin and Beyond." *Organizational Studies* 29.4: 493–500.

Bernardini, Claudia et al. (2001): "How to Improve the Readability of the Patient Package Leaflet: A Survey on the Use of Colour, Print Size and Layout." *Pharmacological Research* 43.5: 437–443.

Berry, Dianne C. (2006): "Informing People about the Risks and Benefits of Medicines: Implications for the Safe and Effective Use of Medicinal Products." *Current Drug Safety* 1.1: 121–126.

Berry, Dianne C. et al. (1997): "What Do Patients Want to Know about their Medicines, and What Do Doctors Want to Tell Them? A Comparative Study." *Psychology & Health* 12.4: 467–480.

Bhatia, Vijay K. (2010): "Interdiscursivity in Professional Communication." *Discourse & Communication* 4.1: 32–50.

Bhatia, Vijay K. (2012): "Critical Reflections on Genre Analysis." *Ibérica* 24: 17–28.

Björnsdóttir, Ingunn/Almarsdóttir, Anna Birna/Traulsen, Janine Morgall (2009): "The Lay Public's Explicit and Implicit Definitions of Drugs." *Administrative Pharmacy* 5.1: 40–50.

Burke, S. E. (2008): *The Doctor-Patient Relationship: An Exploration of the Trainee Doctor's Views. A Thesis Submitted to The University of Birmingham for the Degree of Doctor of Philosophy.* 05.05.2011 <http://etheses.bham.ac.uk/125/1/Burke07PhD.pdf>.

Caron-Flinterman, J. Francisca/Broerse, Jacqueline E. W./Bunders, Joske F. G. (2005): "The Experiential Knowledge of Patients: A New Resource for Biomedical Research?" *Social Science & Medicine* 60.11: 2575–2584.

Consumers' Association (2000): *Patient Information Leaflets: Sick Notes?* London: Consumers' Association.

Cronin, M./O'Hanlon, S./O'Connor, M. (2011): "Readability Level of Patient Information Leaflets for Older People." *Irish Journal of Medical Science* 180.1: 139–142.

Department of Health (2001): *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*. London: Department of Health.

Derrida, Jacques (1982): *Margins of Philosophy* (Alan Bass Trans.). Chicago: University of Chicago Press.

Dixon-Woods, Mary (2001): "Writing Wrongs? An Analysis of Published Discourses about the Use of Patient Information Leaflets." *Social Science & Medicine* 52.9: 1417–1432.

Duggan, Patrick S. et al. (2006): "The Moral Nature of Patient-Centeredness: Is it 'Just the Right Thing to Do'?" *Patient Education and Counseling* 62.2: 271–276.

Engel, George L. (1977): "The Need for a New Medical Model: A Challenge for Biomedicine." *Science* 196.4286: 129–136.

Fage-Butler, Antoinette Mary (2011): *Towards a New Kind of Patient Information Leaflet? Risk, Trust and the Value of Patient Centeredness*. Aarhus: Aarhus University.

Fløttum, Kjersti (2010): "EU Discourse: Polyphony and Unclearness." *Journal of Pragmatics* 42.4: 990–999.

Fløttum, Kjersti/Dahl, Trine (2011): "Climate Change Discourse: Scientific Claims in a Policy Setting." *Fachsprache. International Journal of Specialized Communication* 33.3–4: 205–219.

Foucault, Michel (1973): *The Birth of the Clinic: An Archaeology of Medical Perception* (A. M. Sheridan Trans.). Abingdon: Routledge.

Giere, Ronald N. (2006): *Scientific Perspectivism*. Chicago: University of Chicago Press.

Grime, Janet et al. (2007): "The Role and Value of Written Information for Patients about Individual Medicines: A Systematic Review." *Health Expectations* 10.3: 286–298.

Halbmayer, Ernst (2012): "Debating Animism, Perspectivism and the Construction of Ontologies." *Indiana* 29: 9–23.

Hartzler, Andrea/Pratt, Wanda (2011): "Managing the Personal Side of Health: How Patient Expertise Differs from the Expertise of Clinicians." *Journal of Medical Internet Research* 13.3: 24/04/2012.

Horwitz, Anna/Reuther, Lene/Andersen, Stig Ejdrup (2009): "Patienters Vurdering af Medicinpakningernes Indlægssedler [Patients' Opinions of Patient Information Leaflets]." *Ugeskrift for Læger* 171.8: 599–602.

Hoving, Ciska et al. (2010): "A History of Patient Education by Health Professionals in Europe and North America: From Authority to Shared Decision Making Education." *Patient Education and Counseling* 78.3: 275–281.

Jauffrey-Raustide, Marie (2009): "Self-Support for Drug Users in the Context of Harm Reduction Policy: A Lay Expertise Defined by Drug Users' Life Skills and Citizenship." *Health Sociology Review* 18.2: 159–172.

Kerr, Anna/Cunningham, Sarah/Amos, Amanda (1998): "The New Genetics and Health: Mobilizing Lay Experience." *Public Understanding of Science* 7.1: 41–60.

Kleist, Edward Eugene (2000): *Judging Appearances: A Phenomenological Study of the Kantian Sensus Communis*. Dordrecht: Kluwer Academic Publishers.

Kuhn, Thomas S. (1970 [1962]): *The Structure of Scientific Revolutions.* (2nd ed.). Chicago: University of Chicago Press.

Luhmann, Niklas (1993): "Deconstruction as Second-Order Observing." *New Literacy History* 24.4: 763–782.

Lupton, Deborah (2003): *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London: Sage.

Maruyama, Magoroh (1974): "Paradigmatology and its Application to Cross-Disciplinary, Cross-Professional and Cross-Cultural Communication." *Dialectica* 28.3/4: 135–196.

Maruyama, Magoroh (2004): "Polyocular Vision or Subunderstanding?" *Organization Studies* 25.3: 467–480.

McCormick, James (1996): "Death of the Personal Doctor." *Lancet* 348: 667–668.

McGregor, Sandra (2006): "Roles, Power and Subjective Choice." *Patient Education and Counseling* 60.1: 5–9.

Mead, Nicola/Bower, Peter (2000): "Patient-Centeredness: A Conceptual Framework and Review of the Empirical Literature." *Social Science & Medicine* 51.7: 1087–1110.

MHRA (2005): *Always Read the Leaflet: Getting the Best Information with Every Medicine*. London: The Stationery Office.

Nicolson, Donald J. et al. (2006): "Do Themes in Consumer Medicines Information Literature Reviews Reflect Those Important to Stakeholders?" *Patient Education and Counseling* 64.1/3: 112–118.

Nietzsche, Friedrich (1994[1887]): *On the Genealogy of Morality* (Carol Diethe Trans.). Cambridge: Cambridge University Press.

Noe, Egon/Alrøe, Hugo Fjelsted/Langvad, Anne Mette Sørensen (2005): "A Semiotic Polyocular Framework for Multidisciplinary Research in Relation to Multifunctional Farming and Rural Development." *XXI ESRS-Congress in Hungary. Working Group 3: Sociological Approaches to the Multifunctionality of Agriculture and Rural Areas*: 1–17.

Noe, Egon/Alrøe, Hugo Fjelsted/Langvad, Anne Mette Sørensen (2008): "A Polyocular Framework for Research on Multifunctional Farming and Rural Development." *Sociologia Ruralis* 48.1: 1–15.

Olesen, Frede (2004): "Striking the Balance: From Patient-Centred to Dialogue-Centred Medicine." *Scandinavian Journal of Primary Health Care* 22.4: 193–194.

Olesen, Frede (2012): "God Lægefaglighed er Mere en Medicinsk Faglighed [Good Doctor Competence is More than Medical Knowledge]." *Ugeskrift for Læger* 174.14: 923.

Osimani, Barbara (2010): "Pharmaceutical Risk Communication: Sources of Uncertainty and Legal Tools of Uncertainty Management." *Health, Risk & Society* 12.5: 453–469.

Petersen, Alan (2006): "The Best Experts: The Narratives of Those Who Have a Genetic Condition." *Social Science & Medicine* 63.1: 32–42.

Pollock, Kristian (2005): *Concordance in Medical Consultations*. Abingdon: Radcliffe Publishing.

Raynor, D. K. et al. (2007): "A Systematic Review of Quantitative and Qualitative Research on the Role and Effectiveness of Written Information Available to Patients about Individual Medicines." *Health Technology Assessment* 11.5: i–180.

Raynor, D. K./Dickinson, David (2009): "Key Principles to Guide Development of Consumer Medicine Information: Content Analysis of Information Design Texts." *The Annals of Pharmacotherapy* 43.4: 700–706.

Sarangi, Srikant/Candlin, Christopher N. (2011): "Professional and Organisational Practice: A Discourse/ Communication Perspective" *Handbook of Communication in Organisations and Professions*. Berlin: De Gruyter Mouton. 3–58.

Schicktanz, Silke/Schweda, Mark/Wynne, Brian (2012): "The Ethics of 'Public Understanding of Ethics': Why and How Bioethics Expertise Should Include Public and Patients' Voices." *Medicine, Health Care and Philosophy* 15.2: 129–139.

Shaw, Joanne/Baker, Mary (2004): "'Expert Patient' – Dream or Nightmare?" *British Medical Journal* 328: 723–724.

Smith, Daniel W. (2005): "Deleuze on Leibniz: Difference, Continuity and the Calculus." *Current Continental Theory and Modern Philosophy*. Ed. Stephen/H. Daniel. Evanston, IL: Northwest University Press. 127–147.

Step, Mary M. et al. (2009): "Modeling Patient-Centered Communication: Oncologist Relational Communication and Patient Communication Involvement in Breast Cancer Adjuvant Therapy Decision-Making." *Patient Education and Counseling* 77.3: 369–378.

Stewart, Moira (1995): "Effective Physician-Patient Communication and Health Outcomes: A Review." *Canadian Medical Association Journal* 152.9: 1423–1433.

Stewart, Moira et al. (2000): "The Impact of Patient-Centered Care on Outcomes." *The Journal of Family Practice* 49.9: 796–804.

Thorne, Sally E./Nyhlin, Kerstin Ternulf/Paterson, Barbara L. (2000): "Attitudes toward Patient Expertise in Chronic Illness." *International Journal of Nursing Studies* 37.4: 303–311.

Tuckett, David et al. (1985): *Meetings between Experts: An Approach to Sharing Ideas in Medical Consultations.* London: Tavistock.

van der Waarde, Karen (2008): "Designing Information about Medicine for People." *InfoDesign Revista Brasileira de Design da Informacão* 5.3: 29–39.

van Dijk, Teun A. (2009): *Society and Discourse: How Social Contexts Influence Text and Talk*. Cambridge: Cambridge University Press.

Widdowson, H. G. (2004): *Text, Context, Pretext: Critical Issues in Discourse Analysis*. Oxford: Blackwell.

Antoinette Fage-Butler
University of Aarhus
Business and Social Sciences
Department of Business Communication
fage-butler@asb.dk