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Paul van Der Zande, Arend Jan Waarlo, Mieke Brekelmans, Sanne F  
Akkerman, Jan D. Vermunt

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**A Knowledge Base for Teaching Biology situated in the Context of Genetic Testing**

## Abstract

Recent developments in the field of genomics will impact the daily practice of biology teachers who teach genetics in secondary education. This article reports on the first results of a research project aimed at enhancing biology teacher knowledge for teaching genetics in the context of genetic testing. The increasing body of scientific knowledge concerning genetic testing and the related consequences for decision-making indicate the societal relevance of such a situated learning approach. What content knowledge do biology teachers need for teaching genetics in the personal health context of genetic testing? This article describes the required content knowledge by exploring the educational practice and clinical genetic practices. Nine experienced teachers and 12 respondents representing the clinical genetic practices (clients, medical professionals, and medical ethicists) were interviewed about the biological concepts and ethical, legal, and social aspects (ELSA) of testing they considered relevant to empowering students as future health care clients. The ELSA suggested by the respondents were complemented by suggestions found in the literature on genetic counselling. The findings revealed that the required teacher knowledge consists of multiple layers that are embedded in specific genetic test situations: on the one hand, the knowledge of concepts represented by the curricular framework and some additional concepts (e.g. multifactorial and polygenic disorder) and, on the other hand, more knowledge of ELSA and generic characteristics of genetic test practice (uncertainty, complexity, probability, and morality). Suggestions regarding how to translate these characteristics, concepts, and ELSA into context-based genetics education are discussed.

## Introduction

In the last decennia, science teachers witnessed a shift of focus in science education. Dominant was a disciplinary approach where teaching the structure of science and disciplinary content were the main goals (Aikenhead, 2006; Roberts, 1988). However, not all students show affinity to academic science (Sadler, 2009), and the focus shifted to education relevant for the student's personal life and their preparation for future citizenship, i.e. science lessons that will help them to function in the complex 21st century (Aikenhead, 2006; Kolstø, 2001; Osborne, Collins, Ratcliffe, Millar, & Duschl, 2003; Ryder, 2002). Roberts (1988) discerns a number of meta-perspectives on science teaching. Three of them are perspectives suitable within this focus on relevance for students: a) everyday coping, b) science, technology, and decisions emphasis, and c) self as explainer. Situated learning, or teaching science in context, provides a theoretical framework for supporting student preparation for their future role as citizens (Boersma et al., 2007; Gilbert, 2006; Ratcliffe & Grace, 2003; Sadler, 2009). However, if science teachers adopt a situated learning approach, they need to be aware of the current state of the art in the authentic practice. This article aims to determine what secondary teachers need to know about the field of genetic testing to teach genetics and prepare students for situations in which they may become clients in genetic testing practice. Shulman (1986, 1987) distinguished seven categories of teacher knowledge. One of these categories is pedagogical content knowledge (PCK), which should enable experienced teachers to represent content in such a way that it takes into account the learning difficulties and student conceptions concerning that specific content knowledge. Another category is content knowledge, referring to knowledge about the content to be taught. From a situated learning perspective, it is important to determine the content knowledge of teachers not only by looking at current school subjects, but also by including recent insights from the authentic field, in this case the field of genetic testing. This study explores both the educational practice for the currently used content knowledge on genetic testing, as well as the authentic practice for the needed content knowledge. Before introducing our study, we elaborate in the following sections on situated learning, describe how genetics is currently addressed in

1 secondary education, and briefly review some important developments in authentic genetic test  
2  
3 practice.  
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### 7 *Situated Learning*

9 In his recent review, Sadler (2009) described how the idea that knowing and learning are situated in  
10 social practice gained renewed attention at the end of the last century. The situated learning  
11 approach connects to social-cultural theory by assuming that humans develop through participation  
12 in social cultural practices. Successful participation in practices requires local knowledge and the  
13 appropriate use of artefacts that can make learning meaningful for students. In such a social  
14 practice, people interact with each other and with materials and concepts (Greeno, 1998).

15 Situated learning affects educational practice in at least two ways. First, in this approach the  
16 authentic practice becomes prescriptive and frames what is relevant to learn, thereby defining the  
17 concepts and knowledgeable skills in a meaningful way (Herrington & Herrington, 2006; Lave &  
18 Wenger, 1991). Second, in the situated learning approach students' learning takes place in relation  
19 to a situation that is deduced from the authentic practice. The fact that the authentic practice informs  
20 both the content to be taught and the situational framing of this content is based on the idea that the  
21 authentic context supports the specification of the concept's meaning and brings about the  
22 coherence of concepts within a larger whole (Herrington & Herrington, 2006; Van Aalsvoort, 2004;  
23 Van Oers, 1998). Moreover, because students experience how the concepts can be applied in a  
24 recognisable situation, a situated learning approach aims to provide relevance to the learned content  
25 and promote student motivation (Boersma et al., 2007; Sadler, 2009). Given our interest in content  
26 knowledge, the question arises what knowledge can be derived from authentic practices as the basis  
27 for the required knowledge base of teachers concerned with situated learning. The required  
28 knowledge base needs to include concepts that are relevant to genetic testing practice as well as  
29 knowledge of the situational framing of these concepts. The latter means that teachers should be  
30 able to select and discuss genetic test situations in terms of how they represent the nature of  
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1 decision-making processes in genetic testing practice. This is needed to guide students when they  
2  
3 imagine themselves being clients<sup>1</sup> in a prenatal or pre-symptomatic test situation as the basis for  
4  
5 learning about genetics.  
6

7 To determine the required knowledge base of teachers, it is necessary to acknowledge that 'the  
8  
9 authentic practice' actually includes multiple social practices. The recent Dutch Biology  
10  
11 Curriculum Innovation Programme distinguished three categories of authentic practice for  
12  
13 secondary education: scientific practices, professional practices, and life-world practices (Boersma  
14  
15 et al., 2007). This study aims to derive the required content knowledge of teachers by approaching  
16  
17 people from each of these three practices about relevant concepts and decision-making in genetic  
18  
19 test situations.  
20

### 21 22 *Situated Learning, Education for Citizenship, Socio-Scientific Issues, and Nature of Science*

23  
24 The situated learning approach indicates *how* learning takes place, assuming that learning is an  
25  
26 integral and inseparable aspect of social practice (Lave & Wenger, 1991). The situated learning  
27  
28 approach converges with teaching socio-scientific issues (SSI) and nature of science (NOS), two  
29  
30 approaches that focus more on the *why* and *what* of teaching, stressing that education is meant to  
31  
32 prepare for citizenship (Aikenhead, 2006; Osborne, Collins, Ratcliffe, Millar, & Duschl, 2003;  
33  
34 Ryder, 2001, 2002) Education for citizenship should lay the foundations for decisions and actions in  
35  
36 adulthood in relation to society's controversial science-based problems (Ratcliffe & Grace, 2003).  
37  
38 In a school version of the authentic practice as suggested by Van Aalsvoort (2004), biology lessons  
39  
40 can confront students with controversial issues where they have to learn to clarify their own  
41  
42 position (Aikenhead, 2006; Levinson, 2006; Waarlo, 2003). Controversial issues that have  
43  
44 conceptual as well as procedural connections to sciences, and are viewed as socially significant by  
45  
46 the students, are labelled SSI (Sadler, 2004). Walker and Zeidler (2007) state that through teaching  
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48  
49 <sup>1</sup> Most citizens involved with genetic testing are not ill (yet) and are not referred to as patients but as clients. In this article, the word  
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51 client will be used.  
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1 SSI, students can be empowered to not only reflect on the physical and social world around them  
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3 but also on the (moral) principles behind science-based issues, the decisions made concerning them,  
4  
5 and what those decisions mean in their view of a virtuous life. Authentic situations do not  
6  
7 necessarily reflect SSI. For example, if we discuss animal nutrition in the context of keeping pets at  
8  
9 home, this does not reflect a controversial issue or 'ill structured problem that are the hallmark of  
10  
11 most SSI approaches' (Sadler, 2009, p. 19).

12  
13 In a broader sense, when learning is situated in contexts such as the personal health context of  
14  
15 genetic testing, it also relates to NOS. Although the latter is a complex and contested field (Alters,  
16  
17 1997; Helms & Carlone, 1999; Lemke, 2001), Osborne et al. (2003) discern nine themes within the  
18  
19 field of NOS. Some of these themes fit well in a situated learning approach to genetic testing. For  
20  
21 example, the theme of *science and certainty* is concerned with the notion that much scientific  
22  
23 knowledge is well established and beyond reasonable doubt, but that other scientific knowledge is  
24  
25 not. Knowledge is the current 'state of the art' and is still in progress. For instance, the medical  
26  
27 knowledge used in genetic testing is still developing and will change in the near future because of  
28  
29 new evidence or new interpretations of old evidence. Another aspect of NOS mentioned by Osborne  
30  
31 et al. (2003) that is even more appropriate in the health context of genetic testing does not belong to  
32  
33 the abovementioned nine themes, namely *moral and ethical dimensions in the development of*  
34  
35 *scientific knowledge*. Students who discuss possibilities within the genetic test practice should  
36  
37 realise that some of those choices, although explained in scientific medical terms, are not value free  
38  
39 and can conflict with their moral and ethical values. Although some authors suggest to include more  
40  
41 aspects of NOS in teaching genetics in context, as will be discussed later, NOS defined in the way  
42  
43 of Osborne et al. (2003) is focused on 'science in the making'. Within the life-world practice of  
44  
45 genetic testing, the focus of the educational study reported here, i.e. the moral and uncertain  
46  
47 implications of scientific knowledge for the personal lives of students, is of particular interest.  
48  
49 Then, the focus is more on personal meaning in the student learning process, which is more in line  
50  
51 with a socio-cultural perspective on teaching NOS (Helms & Carlone, 1999; Lemke, 2001), that is  
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1 students who give meaning to knowledge through internal and external dialogue about their own  
2 beliefs, values, and socio-cultural position towards genetic testing issues. In terms of NOS this can  
3 be seen as a mixture between distal and proximal knowledge of NOS. Distal knowledge of NOS can  
4 be operationalized as the understanding of NOS 'as students' explicit knowledge about the  
5 standards, practices, and products of the professional scientific community' (Hogan, 2000, p. 53),  
6 and proximal knowledge is concerned with 'understanding students' notions about their own  
7 process of learning science' (op. cit., p. 54). This idea of personal meaning and decision-making  
8 relates again to the domain of SSI (Kolstø, 2006).  
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### 18 *Needs for Expanding the Curriculum on Genetic Testing*

19  
20 Genetics in secondary education includes the knowledge of relevant curricular genetic concepts and  
21 heuristics such as Punnett squares and genealogical family trees. Recently, it has been argued that  
22 the biology curriculum should shift from focussing on single gene disorders to polygenetic  
23 disorders (Dougherty, 2009), and there is a growing awareness of the need to align the content of  
24 genetic teaching practice with the developments in the authentic practice (Boerwinkel, Verhoeff, &  
25 Waarlo, 2008). The current focus on monogenetic heredity, common in classical Mendelian  
26 genetics, is thought to hinder the necessary insight into the crucial role of variation and  
27 individuality in modern genetics (McInerney, 2002), and does not prepare our students for effective  
28 participation as medical consumers (Dougherty, 2009). Other authors suggest the introduction of  
29 NOS aspects such as collecting and interpreting data or the uncertainty of scientific information  
30 (Ryder, 2001). Although the number of publications on teaching genetics in this controversial  
31 genetic test practice is substantial, the majority of the work focuses on higher education (Challen,  
32 Harris, Benjamin, & Harris, 2006; Guttmacher, Porteous, & McInerney, 2007; Hott et al., 2002;  
33 McInerney & Collins, 2007; Plass, Baars, Beemer, & Ten Kate, 2006). Moreover, most of these  
34 studies concentrated on the context of one or two diseases only, e.g. breast cancer, and most used  
35 Mendelian concepts such as gene, mutation, and family-related heredity chances (Richards,  
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1 & Guyer, 2003). The practice of genetic testing also makes things complex because genetic testing  
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3 is a complex process itself. Mostly, genetic testing is a so-called 'fact-and-value' issue, and these  
4  
5 issues require an analysis that reflects different disciplines and perspectives (Yesley, 2008). Test  
6  
7 situations differ from other medical situations because of the independency of the actual medical  
8  
9 status, for instance one does not have to be ill at the time for a test to be useful. Moreover, the  
10  
11 permanency of the genetic traits, implications for relatives, and problems clients possibly face with  
12  
13 identity adds to the complexity (Nyrhinen, Leino-Kilpi, & Hietala, 2004). Consequently, clients are  
14  
15 faced with an increasing number of decisions, each with its own ethical, legal, and social  
16  
17 implications. More and more, society expects its citizens to be capable of making reasonable  
18  
19 decisions on these kinds of controversial issues. Therefore, one must be able to weigh scientific and  
20  
21 biotechnological information together with ethical or legal considerations (Gearon, 2003) in a  
22  
23 complex social setting (Veugelers & Vedder, 2003). Thus, if teachers want to prepare their students  
24  
25 for future decision-making, they do not only need an accurate knowledge of concepts but also a  
26  
27 knowledge of the situational framing of these concepts, e.g. the ethical, legal and social aspects  
28  
29 (ELSA) of genetic testing. In the literature, several systematic process descriptions of handling  
30  
31 controversial issues, medical consultations in general, and the genetic testing process in particular  
32  
33 can be found (e.g. Decruyenaere, 2003; Nyrhinen et al, 2004; Pin & Gutteling, 2005; Resnik, 2003;  
34  
35 Rowley, 2007; Van Neste, 1993; Wilfond, 1995). For instance, some research has been undertaken  
36  
37 on public awareness and opinion about genomics (Pin & Gutteling, 2005), on the ethical aspects  
38  
39 (Nyrhinen et al, 2004), or the decision-making (Rowley, 2007). However, none of these  
40  
41 descriptions are all inclusive or aimed at secondary education. Such a description is one of the  
42  
43 sought-after outcomes of the study reported here. What can be derived from the literature is that the  
44  
45 decision-making process within genetic testing, the authentic practice we were looking for, can be  
46  
47 divided into the following four stages (Bolt et al, 2005; Decruyenaere, 2003; Grient Dreux,  
48  
49 Kooijman, & Korenromp, 2008; Nyrhinen et al, 2004).

50 Stage 1: Preparation phase, gathering information;  
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1 Stage 2: Weighing information and decision-making 1;

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3 Stage 3: The laboratory, analytical phase; and

4  
5 Stage 4: The post-analytical phase – weighing information and decision-making 2, interpretation  
6  
7 and processing the results (consequences), and support.

8  
9 In this article, we will concentrate on knowledge concerning stages 1 and 2 because most problems  
10  
11 emerge in these pre-analytical phases (Nyrhinen et al, 2004). As the results of the study will show,  
12  
13 the first two stages are more relevant for education in this context. Furthermore, these problems are  
14  
15 most informative to students not only because they are well aware they might think differently  
16  
17 when they are adults and real clients, especially in stage 4 (Van der Zande, Brekelmans, Vermunt,  
18  
19 & Waarlo, 2009), but also because in stage 4 clients go through the same kinds of processes as in  
20  
21 phase 1 and 2, only now they are focused on accepting test outcomes.  
22

#### 23 24 25 *Analytic Framework for Determining Required Content Knowledge*

26 This article aims to determine the required teacher content knowledge for teaching biology in the  
27  
28 genetic testing context. What specific content knowledge is required on relevant concepts and the  
29  
30 situational framing of these concepts in the processes of decision-making? The relevance of specific  
31  
32 content knowledge for context-based education or teaching controversial socio-scientific issues has  
33  
34 been stressed by several authors (Klop & Severiens, 2007; Levinson, 2006; Levinson & Turner,  
35  
36 2001; Sadler, 2009; Zeidler, Sadler, Simmons, & Howes, 2005). However, a tailored description of  
37  
38 the content knowledge used in authentic practices, e.g. in the health context of genetic testing, is to  
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40 the best of our knowledge not available. If we accept the assumption stated above that in a social  
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42 practice relevant knowledge is helpful or necessary for the successful participation in that practice,  
43  
44 we have to explore this authentic practice to find out what this knowledge is. Consequently, if we  
45  
46 want to find out what is new in this content knowledge compared with current content knowledge in  
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48 secondary education, we have to compare this authentic practice-based knowledge claim with the  
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1 current content knowledge already being taught by experienced biology teachers. Our research  
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3 question can be formulated as follows:  
4

5 What content knowledge do biology teachers need to teach genetics in the personal health  
6  
7 context of genetic testing?  
8

- 9 1. What is the content knowledge experienced teachers use when they teach genetics in  
10 the personal health context of genetic testing?  
11
- 12 2. What is the content knowledge that can be derived from participants in the authentic  
13 practice of genetic testing?  
14  
15

16  
17 Based on the earlier accounts of situated learning and the current developments in the field of  
18 genetic testing, required knowledge can be seen as related to different layers of the authentic  
19 practice as pictured in Figure 1. As stated above, within the situated learning approach learning  
20 takes place in relation to a situation; a specific client considering a specific test (grey-dotted box in  
21 Figure 1). This specific situation must be selected so that it represents the nature of the overarching  
22 medical practice of genetic testing (outer box in Figure 1). In the test situation, the concepts  
23 relevant for a proper understanding of genetic testing are under discussion (inner box Figure 1).  
24  
25 Since the Human Genome Project, several researchers have suggested rethinking the biology  
26 curriculum, stating that it needs to also address the ELSA that are inherent to the decision-making  
27 processes in genetic testing practice (Baars et al., 2005; Boerwinkel, Verhoeff, & Waarlo, 2008;  
28 Harvey et al., 2007; McInerney, 1995, 2002) (grey box in Figure 1). If teachers aim to empower  
29 students for their future role as health-care clients in genetic test situations, their required content  
30 knowledge must take account of these four layers of knowledge of the authentic practice. For the  
31 current biological content knowledge, used in today's biology classes, we explored educational  
32 practice by eliciting and describing the content knowledge of experienced teachers. Expertise is  
33 supposed to emerge only after long experience. Expert teachers have taught at least 10,000 contact  
34 hours (Ropo, 2004). In The Netherlands, that equals at least nine or 10 years of professional  
35 practice.  
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1 In this study the knowledge and experiences of medical professionals and clients involved in genetic  
2 counselling were sought to inform us about the knowledge used in authentic clinical genetic practice.  
3 They could suggest what might be worthwhile for students to become prepared citizens, and this  
4 content knowledge can be compared with what is already taught in classrooms.  
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9 Insert Figure 1 about here  
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#### 14 Method

##### 15 *Participants*

16 For the exploration of the current state of domain knowledge in teaching expertise, nine  
17 experienced biology teachers were interviewed (Bt1–Bt9). This non-random typical case sample  
18 (Onwuegbuzie & Leech, 2007) was selected from a list provided by biology teacher educators of  
19 the four biggest teacher education institutes in The Netherlands. These teacher educators were  
20 asked to provide us with names of teachers who were known for their expertise in teaching biology  
21 in context or were known for discussing SSI with their students. The actual selection was based on  
22 convenience (Ibid, 2007, p. 114); we received 15 names from the teacher educators and nine were  
23 available. The teachers were from eight different schools, with an average teaching experience of  
24 20.7 years. Three out of the nine were female. Two worked at vocational schools, two in pre-  
25 university classes, and five at schools with vocational and pre-university education. Five worked at  
26 schools with a religious denomination (three catholic, two protestant) and four worked at public  
27 schools.  
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29

30 To investigate the expertise that can be elicited from the clinical genetic practice, a stratified sample  
31 was used; 12 stakeholders were interviewed individually: four clients (C1–C4), four medical  
32 professionals (P1–P4: two physicians; one clinical geneticist, and one genetic counsellor), and four  
33 medical ethicists (Me1–Me4). The names of the medical ethicists and professionals were provided  
34 to us by the head of a science communication institute in the field of genomics. The ethicists  
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1 represented four different academic medical centres. The medical professionals came from different  
2 cities and provided us with the names of their clients. Each of the three groups consisted of two  
3 females and two males. These three groups were not intended for comparative analysis, but to  
4 ensure data from different perspectives on genetic testing.  
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### 10 *Instrumentation*

11  
12 Three instruments for data gathering were used. First, the teachers were interviewed in their own  
13 school buildings using a semi-structured face-to-face interview of 60 to 75 minutes. In the  
14 interviews, they were questioned about the content they taught in their genetic lessons. They were  
15 asked to compare the taught concepts with the formal Dutch curriculum. Concerning context-based  
16 knowledge of prenatal and pre-symptomatic genetic testing they were asked whether they had  
17 actually taught genetics in the context of genetic testing, what other concepts or knowledge became  
18 relevant in the classroom because of this context, and whether they discussed the ethical or other  
19 aspects of the test situation with their students in their lessons.  
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28 Second, the referents from the authentic genetic testing practice were interviewed using a semi-  
29 structured face-to-face interview. The referents were interviewed for 60 minutes in their offices or  
30 homes (the clients). They were questioned about what clients must know or be able to do when they  
31 were supposed to participate successfully in a genetic testing situation, i.e. what biomedical  
32 concepts they considered relevant and what kind of knowledge they considered important within the  
33 process of genetic testing.  
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40 The interviews were recorded and imported as audio files into the software Atlas-ti (Murh, 2006).

41 Third, because the ELSA mentioned in the interviews with the referents turned out to be exemplary  
42 rather than all inclusive, the ELSA suggested by the referents were complemented and ordered by  
43 suggestions found in the literature on the ELSA of genetic testing using the search engines Google  
44 Scholar and Omega with search criteria such as (prenatal) genetic testing, diagnostic genetic testing,  
45 moral aspects, ELSA, health-care, and care ethics in different combinations.  
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*Data Analyses*

To answer the main research question, three analytic steps were undertaken. A first step entailed determining the current content knowledge of the experienced biology teachers. This was done by (a) looking at the extent to which the teachers taught biology concepts according to the formal Dutch curriculum, (b) listing possible additional concepts relevant to genetic testing, and (c) determining their familiarity with ELSA. Second, the required content knowledge of teachers was determined by analysing the interviews of the 12 referents from the authentic practice on genetic testing. Finally, the ELSA suggested by the respondents were complemented by suggestions found in the literature on genetic counselling.

To show how those concepts mentioned by the referents fitted into a formal curriculum, the latest curriculum from the Dutch Biology Curriculum Innovation Board (CVBO) was considered the formal curriculum in this study (Boersma et al., 2007). The mentioned concepts were arranged into the concept matrix used by the CVBO to illustrate the coherence among biological concepts (Table

2). In this matrix, each concept was functionally placed within the organising framework of systems biology. Some concepts mentioned by the referents were related to human activities in the context of genetic testing, and were not yet part of the official CVBO concept matrix. These are presented separately as an added row to the matrix. The placing of new concepts into this matrix was discussed with two other researchers in biology education, one of them the chair of the CVBO, until consensus was reached. During the coding of the interviews we worked iteratively between the interview data and ELSA found in the literature. In the additional literature search, a saturation strategy was used. Reading stopped, after reading 35 books and articles, when the last two articles provided no single new moral consideration or dilemma and informational redundancy was reached (Onwuegbuzie & Leech, 2007). These articles and books are listed separately in the references. For coding we used a grounded theory approach (Glaser & Strauss, 1999). The suggestions from the referents and the literature were coded in an open way (Boeije, 2010), the interviews were

Deleted: 1

1 fragmented, and the fragments were then compared among one other before being categorised and  
2  
3 recategorised iteratively by the researcher with the findings from the literature and labelled with a  
4  
5 code. This resulted, for instance, in the extensions of 'social' into 'psychosocial' in the ELSA  
6  
7 codes. The inter-rater reliability of the three main codes (concepts, ELSA, and characteristics) were  
8  
9 checked by another genomics researcher by comparison with the scoring of 18 interview fragments  
10  
11 within these three categories:  $n = \text{number of categories}$  (Cicchetti, 1976) and  $2n^2 = 18$  (Cohen's  
12  
13 kappa = 0.87). Some of these fragments were rather lengthy, when the referents started e.g. with  
14  
15 discussing a characteristic of the genetic test practice, then illustrated it with an ELSA, and using  
16  
17 different biomedical concepts in both parts of the fragment. More than one code could be linked to  
18  
19 these fragments. Within the main code 'characteristics', the four codes (uncertainty, probability,  
20  
21 complexity, and morality) were checked for inter-rater reliability by comparing the scoring of  $2n^2 =$   
22  
23 32 interview fragments within these four subcategories (Cohen's kappa = 0.74). Finally, the  
24  
25 Cohen's kappa of the three ELSA codes was determined (0.71). To illustrate the coding categories  
26  
27 used in the analyses some examples are listed in Table 1, with the corresponding utterances from the  
28  
29 referents. In the end, the findings were summarised in two of the four stages of the decision-making  
30  
31 process mentioned above:

32 Stage 1: Preparation phase, gathering information; and

33 Stage 2: Weighing information and decision-making 1

34  
35  
36 Insert Table 1 about here

37  
38  
39  
40 Results

41  
42 *Educational Practice*

43  
44 Answering our research question about the content knowledge they used when teaching genetics in  
45  
46 the personal health context, all experienced biology teachers reported that they taught the concepts  
47  
48 mentioned in the Dutch examination syllabus (Table 2).

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1 I used to concentrate on the classical heredity questions with **Punnett squares** etc. (Bold  
2 added by authors). And of course they had to understand everything about **DNA duplication**,  
3 and I used a strategy of travelling through the different **organisation levels**, extended with a  
4 practical, a cut, paste and paint assignment where they really had to make a model of **DNA**  
5 **transcription**. But now, although I still incorporate these issues, I'm engaged in a CVBO-like  
6 context around a cystic fibrosis patient, so I focus also on the symptoms of this disease and  
7 they have to use a concept from cytology like **membranes** etc.' (Bt1).

8 'With the national curriculum in mind, we try to link the classic genetics with concepts like  
9 **dominant, recessive, homozygote, and heterozygote to DNA**, but unfortunately our method  
10 treats them separately' (Bt2; see also Quotation 1 in [Table 1](#)).

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11 Only one teacher mentioned the importance of an additional concept not included in the formal  
12 curriculum: '**epigenetic factors**' (cf. Q3 in [Table 1](#)). The fact that the teachers taught in accordance  
13 with the formal curriculum was explained by their major concern to have their students pass the  
14 exams. One of the teachers (Bt2) even mentioned the national curriculum seven times as a reference  
15 point during the interview.

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16 Some ELSA of genetic testing were distinguished by the teachers. Because they had also gained life  
17 experience, they all were familiar with some ELSA of genetic testing. These experienced teachers  
18 were able to recognise these aspects when they were confronted with them during their lessons.

19 'In discussing positive test outcomes ... I use the film "It's in the genes" of the Dutch  
20 Alliance of Genetic Interests Groups. At the end, one of the three brothers who were tested  
21 appears not to have the genetic predisposition for thyroid cancer, and I always hold the film  
22 for a moment there to point out to them that this boy feels emotionally disconnected from the  
23 rest of the affected family members' (Bt1).

24 These feelings were labelled in the literature as feelings of isolation and guilt (e.g. Decruyenaere,  
25 2003; Wilfond, 1995). However, the interviews revealed that the familiarity with ELSA differed  
26 from teacher to teacher, and most teachers (seven out of nine) explicitly mentioned the importance

1 of becoming more aware of different ELSA for their future teaching because they considered them  
2  
3 an inherent part of the context-based content.  
4

### 7 *The Authentic Practice of Genetic Testing*

9 First, from the assumption that clients were familiar with the medical framework of their test  
10 situation, they mentioned a number of biomedical concepts teachers should know to teach context-  
11 based genetics. Next, some ELSA of genetic testing were labelled important and, consequently,  
12 should be part of the required teacher knowledge. However, the majority of the referents indicated  
13 that for preparing students for genetic testing teachers should be aware of the four characteristics of  
14 genetic practice: the uncertainty (nine out of 12 referents), probability (10 out of 12), complexity  
15 (10 out of 12), and morality (12 out of 12) of testing (outer box of Figure 1). However, to  
16 understand these characteristics and accept the consequences of, say, the complexity of genetics for  
17 your life, a knowledge of biological concepts seemed to be necessary (inner box of Figure 1). To  
18 illustrate how all these concepts, ELSA and characteristics are interwoven in real life, this section  
19 ends with the story of Anne, one of the client-referents. Her story is an illustrative case study, based  
20 on a dense composition of quotations from her interview. Anne is a mother of two sons, one with a  
21 muscle disability, who looks back on her acquaintance with the world of genetic testing during the  
22 pregnancy of her third child (Box 1). We will discuss how the findings are reflected in this story.  
23  
24

### 25 *Medical Framework*

26 The referents in the authentic practice made it clear from the beginning that when clients have to  
27 decide on a genetic test, they first have to know what kind of heritable diseases they are looking for  
28 (including causes, symptoms, life expectations, possible treatments (cf. Q6 in [Table 1](#)), and side  
29 effects), and which tests are available (pre-implementation, prenatal, pre-symptomatic). This  
30 medical information is inherent to genetic test practice (grey-dotted box in Figure 1). However, to  
31 understand this medical information clients must also have additional knowledge. The interviews  
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1 with the participants in clinical genetic practices resulted in three sets of data, all informing the  
2  
3 context-based knowledge base for teaching in this authentic practice.  
4

### 5 *Biological Concepts*

6  
7 The referents underlined the importance of sound conceptual knowledge. First, most concepts  
8  
9 mentioned in standard curricula were relevant in their eyes (Q2, [Table 1](#)). Some clients indicated  
10  
11 that not understanding these concepts was a problem for them.  
12

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13 'I did not know enough about genetics, and I do not understand **probability** at all. What I  
14  
15 wanted to know and understand was how those tests worked and what they were looking for.  
16  
17 I do not understand how this disorder is linked to **genes** or something, and although I am  
18  
19 highly educated, I have no affinity with genetics and probability' (C1).  
20

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21 The professional referents also mentioned extracurricular concepts (Q4, [Table 1](#)):  
22

23 'Ok, you have Mendel, the **high risk genes**, and concepts like **dominant** or **X-**  
24  
25 **chromosomal**, but they also need to understand the **low-risk genes**, the **polygenetic** setting  
26  
27 where gene a + gene b + gene c + **environment** can also lead to a disorder' (P1).  
28

29 'I think that everybody has to understand that, when **one nucleotide** in your **DNA** changes,  
30  
31 that does not always indicate that you will become ill, but that it adds a little to the **risk** you  
32  
33 are running. And that such a change only leads to trouble when for instance you also get a  
34  
35 virus infection. Students have to understand the **genome variation** and must be able to  
36  
37 accept the complexity, the uncertainty, and the relative certainty' (P4).  
38

39 New concepts mentioned by the referents of the authentic practice that were not yet part of the  
40  
41 CVBO concept matrix were added in bold in the matrix ([Table 2](#)). This approach of teaching  
42  
43 science in context, which implies that the context indicates what concepts are relevant to teach, can  
44  
45 increase the total number of concepts being taught.  
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48 Insert [Table 2](#) about here  
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ELSA

Part of the teacher content knowledge of this medical health context are the ELSA of genetic testing. According to the referents of the authentic practice, these ELSA were not student content *per se* but should be part of a teacher's knowledge to recognise emerging ELSA during class discussions and provide them with language to clarify unclear student remarks, emotions, or intuitions. In the four stages of medical decision-making concerning genetic testing, the following aspects mentioned by the referents can be taken into account.

*Stage 1: Preparation phase, gathering information.* The first decision a client makes is whether she wants to have a test. There are different arguments for wanting to know or not wanting to know the test outcome:

- Ethical: religious arguments or arguments of responsibility and care, e.g. can you avoid harm and sorrow? (Q7, [Table 1](#));
- Legal: is it legal; is the 'right not to know' applicable? (Wilfond, 1995); and
- Psychosocial aspects (Q8, Q9, Q12, Q13, [Table 1](#), and Box 1): reassurance, feelings of (un)certainity, relief, guilt, isolation, anticipating decision regret, (in)dependency, responsibility, taboo, discrimination, stigmatisation, complexity, and timing (e.g. Nyrhinen, Hietala, Puukka, & Leino-Kilpi, 2007).

After clients have decided that they want to know their genetic predisposition or that of their baby, the process of *gathering information* starts, and a lot of questions and knowledge can be relevant.

- Ethical: mostly the four principles of biomedical ethics are at stake – patient autonomy, beneficence, non-maleficence, and justice – completed with the principles of informed consent, privacy, care, and solidarity. Is there a conflict of interest? Which values are important for the client and what do they mean for her?
- Legal: what are the consequences for work, loans, and insurance?

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- Psychosocial: who is involved? (Q10, Q11, [Table 1](#)) What about the carrying capacity of the family (Box 1)? Can the client cope (emotionally) with a change of perspective, as is illustrated by the following quote from an expectant mother?

‘The most striking aspect of the decision-making process was that I did not know Sophia. I had to make decisions on behalf of a person whose identity was undeclared, unknown, and unknowable’ (Rosner, 2004, p. 20).

*Stage 2: Weighing information and decision-making 1.* After gathering information, stage 2 starts with the weighing process. Before deciding to undergo a test, the client has to examine, for instance, whether they understand the complex information, what it means to them, and whether they and their social environment can deal with it emotionally (Box 1). How are the values at stake balanced? Are the identified interests met and is help needed or not. After communicating the test outcome (stage 3, the *laboratory, analytical phase*), either positive or negative, a client must formulate a personal meaning (stage 4, *interpretation and processing the results, consequences*). Sometimes the difficult question of abortion is acute in a very short timeframe (Box 1), but in all cases emotions are involved and follow-up questions of responsibility and social consequences arise. Who else should be notified (Q10, Q11, [Table 1](#)): children, other family members, parents, or siblings? And finally, some questions are still unanswered: when, how serious, and how fast will the disease develop?

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Most problems can be found in stage 1, and concern the issue of informed consent. If students assume the position of a client, the question is whether or not they can understand everything. Can they assess the pros and cons, the risks, their own ethical position, and the medico-legal, emotional, and psychosocial consequences (Nyrhinen et al, 2004)?

#### *Characteristics*

Four characteristics relevant to the authentic genetic practice came to the fore, presented here by exemplary quotations.

1            *Uncertainty.* Entering the consulting room of a doctor or genetic counsellor, people often  
2  
3 expect to find straightforward answers and clear cut solutions. However, one cannot shape life  
4  
5 according to one's own desires and directions (Box 1).  
6

7            'Most people have inadequate knowledge of what is possible nowadays. They have  
8  
9 unrealistic expectations and do not understand the nature/nurture aspects' (Me1).

10 Moderation of these high expectations by future clients is one of the educational goals mentioned  
11  
12 by the referents (Q15, [Table 1](#)). To understand the uncertainty of genetics, concepts such as  
13  
14 'genomic variation', 'high and low risk genes', and 'single nucleotide polymorphisms' are  
15  
16 important.  
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18            *Probability.* The referents agreed on the importance of a proper understanding of  
19  
20 probability.  
21

22            'Risks are evaluated situationally. Risks of close events, e.g. of getting ill, are overestimated,  
23  
24 and more far away risks, e.g. risks you run in traffic, are underestimated. Even the language  
25  
26 to present risks to people influences their perception' (Me1).  
27

28 Not only did the professionals stress this point. The clients also mentioned that this was one of the  
29  
30 most difficult aspects for them to grasp, and as a consequence, knowing the chance did not help at  
31  
32 all (Box 1). Concepts such as 'chance' and 'risk assessment' help understand genetic probability.  
33

34            *Complexity.* The referents stressed the importance of understanding the complexity of  
35  
36 heredity.  
37

38            'In the beginning most clients don't see the difference between confirmation and excluding  
39  
40 possibilities. Confirmation is sometimes possible, ruling out mostly not' (P1).  
41

42            'It is not a one-to-one relation between gene and disease. Students must understand the  
43  
44 complexity of the numerous genes involved in a disease' (P2).  
45

46 Often things are even more complex, and then clients do not go through these stages in an orderly  
47  
48 way, and report other characteristics that influence their decision.  
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- The process is cyclic; clients go through some of the stages more than once. It is possible that, after learning some of the consequences, you no longer want to have a test, although you started out wanting it (Q10, [Table 1](#));
- The complexity of the process can be perceived as confusing and can cause all kinds of emotions (Q20, [Table 1](#));
- The process is under time pressure; preparation for this time pressure is one of the arguments the referents had for teaching genetics in this context (Box 1, Q8, [Table 1](#));
- Choices are not only difficult, sometimes they have to be made in a chaotic and detached context. In this perspective, referents said that it is important that students learn how to personally reflect, even more than learning genetics and ethics (Q17, Q18, [Table 1](#)). What does it mean to be that ill? For your child or for you?; and
- According to the referents, emotional and rational considerations are important in education. One client confirmed the importance of these considerations by going even one step further by stating that rational considerations didn't help at all (Q19, [Table 1](#)).

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To understand the complexity of genetics, concepts such as 'multifactorial disorder', 'polygenic disorder', and 'genetic polymorphism' are also important.

*Morality.* According to the professionals, to be capable of making responsible decisions concerning genetic testing, one should also know something about ethics.

'Also certain values, principles, and moral experiences are relevant for this kind of considerations; respect for autonomy, the principle of human dignity, prima facie duties like non-injury. If you only reflect on intuitions or your own experiences, the narratives, it will not be enough' (Me2).

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Knowledge alone is not enough; what does this information mean? (Q17, Q18, [Table 1](#)). The referents suggested that it could be informative to students to step out of the personal context and take a societal perspective. Then, a number of overarching issues can be raised including

desirability, respectability, and the protection of the weak and those without voice (Q22, Q23, [Table 1](#)).

Or, what ethicist label 'expressive aspect' of an argument, and was voiced by Albert (2003):

'If society condones searching out and eliminating people like me, what does this say about how I am valued by others and how I should value myself?' (Albert in Levinson & Reiss, 2003, p. 115).

And finally, are there (no) limits in what we can do or want to manipulate? Is this a personal responsibility or do we have enough societal guidance and legal regulations? In other words, do our ethics meet our medical and technical possibilities? According to the referents, these are important issues to address in education.

#### *The Story of Anne*

When teachers want to situate student learning in authentic practices such as genetic testing, they must be able to fathom the complex cases so typical of these practices. The experience of Anne, one of our client-referents, is an example of such a case and illustrates several of our findings. First, it is the specific authentic practice that prescribes the content knowledge and shapes the ELSA relevant for successful participation in the authentic practice: opting for a test with its possible far-reaching consequences. Anne's lack of biomedical knowledge, e.g. the biomedical background of the triple test, and her struggle with the concept of chance illustrates the first. The latter is shown by her emotional confusion, how she anticipated her decision regret, the role of others, her own background, and how she surveyed her carrying capacity. Next, her story illustrates the four common characteristics inherent to genetic testing practice, i.e. the difficulty she had with probability and the uncertainty of the situation. In fact, her story reflects one big ethical struggle, what to do in this complex situation, and why? Looking back on it now, she can voice it, but she would have been helped at the time had her biology teacher discussed this perspective with her.



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Insert Box 1 about here

#### Conclusion and Discussion

What content knowledge do biology teachers need to teach genetics in the personal health context of genetic testing? Current educational practice shed some light on the content knowledge we were looking for. This encompassed sound conceptual knowledge, included in the formal curriculum and necessary to help students pass their exams; concepts such as dominant, recessive, homozygote, heterozygote, DNA duplication, and transcription. The referents of the authentic practice brought up several other biological concepts, such as high risk genes, low risk genes, multifactorial disorders, and polygenic disorders (Table 2). According to them, these concepts are necessary for understanding the characteristics of uncertainty, complexity, probability, and morality. These characteristics were considered relevant for successful decision-making in genetic testing. Finally, the authentic practice, complemented by the relevant literature, provided an overview of the ELSA of genetic testing, which can be presented to teachers in four stages. These ELSA included ethical issues of informed consent and solidarity, dilemmas such as that between patient autonomy and guilt, legal issues concerning insurance, and social implications for relatives or future children (Table 1). Some of these ELSA were familiar to the expert teachers, but that differed depending on a teacher's life experience. Most thought it relevant to become more aware of these ELSA for their future teaching.

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To the best of our knowledge this is the first time the authentic practice of genetic testing has been explored for the possible content knowledge of context-based biology teaching.

We started from the basic assumption of situated learning that the authentic practice is prescriptive and frames what is relevant to learn (Lave & Wenger, 1991). The literature (e.g. Boersma et al., 2007; Nyrhinen, Leino-Kilpi, & Hietala, 2004) gave us reason to believe that

1 information about relevant knowledge and ELSA could be provided by the referents of the  
2  
3 authentic practice. The results of this study confirmed this expectation.  
4

5 This study, as some extracurricular developments, aim to introduce more contemporary  
6 concepts and genomics research techniques in school biology (Dougherty, 2009; Mil, Boerwinkel,  
7 Buizer-Voskamp, Speksnijder, & Waarlo, 2010). However, most of the concepts mentioned do not  
8 form a part of the formal curriculum, and also exceed some earlier recommendations that were  
9 limited to the more classical Mendelian concepts (Richards et al., 1995). This might be an important  
10 side effect. If each context that will be explored to facilitate authentic learning results in  
11 extracurricular concepts, the issue of an overloaded biology curriculum must be addressed..  
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19 The recommendation of the referents to include the specific ELSA of genetic testing in  
20 biology education and their descriptions is helpful for describing the knowledge base for teachers  
21 who want to prepare students for the complexity of the testing situation. These ELSA could also  
22 help the debate on education for citizenship concerning this social practice (e.g. Aikenhead, 2006;  
23 Levinson & Turner, 2001; Ratcliffe & Grace, 2003).  
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28 The referents put an unforeseen emphasis on the characteristics of uncertainty, complexity,  
29 probability, and morality. This idea can be informative for biology teachers who want to apply the  
30 authentic learning approach because these characteristics are best understood via extracurricular  
31 concepts. For understanding uncertainty in genetics, for instance, the concepts of 'genomic  
32 variation', 'high and low risk genes', and 'single nucleotide polymorphisms' are needed. Moreover,  
33 concepts such as 'chance' and 'risk assessment' help explain genetic probability. The emphasis on  
34 the characteristics of morality and complexity underlined the fact that genetic testing is a socio-  
35 scientific issue. Clients in a genetic test situation are confronted with a controversial and ill  
36 structured problem (Levinson, 2006; Sadler, 2009). Test outcomes are not always as unambiguous  
37 as they want them to be, and clients have to weigh scientific and medical information with complex  
38 social and ethical consequences, while rational considerations fall together with emotional  
39 confusion.  
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1 The emphasis on the characteristic of uncertainty joins in with the discussion about the NOS  
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3 and affirms its place in science education (Cobern, 2000; Lederman, 1999; Meichtry, 1999;  
4  
5 Osborne, Collins, Ratchliffe, Millar, & Duschl, 2003; Ryder, 2001). Ryder (2001) states that the  
6  
7 knowledge of the role of uncertainty in science is one of the main areas of relevant science  
8  
9 knowledge for functional scientific literacy. Next, insight in the making of science can also  
10  
11 influence students' own learning of science (e.g. Hogan, 2000). The author's description of the  
12  
13 possible interaction between the distal and proximal knowledge of NOS is of interest within our  
14  
15 focus on student learning. According to Hogan, it could be that stimulated reflection in the two  
16  
17 areas recursively supports the development of both. The distal knowledge of NOS, or the  
18  
19 'knowledge about the enterprise of professional science, including the epistemological  
20  
21 commitments that undergird the formation and judgment of scientists' knowledge claims' (Hogan,  
22  
23 2000, p. 62), could influence the proximal knowledge of NOS, or the 'metacognitive knowledge  
24  
25 about and perspectives on personal experiences in scientific sense-making (i.e., learning), and  
26  
27 personal epistemological commitments about scientific knowledge and knowing, especially in  
28  
29 school contexts' (Ibid, 2000, p. 62), and vice versa.

30 This study focused on what teachers should know to prepare their students for the making of  
31  
32 personal meaning of scientific knowledge rather than on broader socio-cultural aspects. We did not  
33  
34 discuss aspects such as the economic, sociological, and political role of science in our modern  
35  
36 world, the sociology of science, or the way science is practised and constructed by society  
37  
38 (Brickhouse, 2001; Cunningham & Helms, 1998; Lemke, 2001). In our view, these perspectives  
39  
40 should be discussed with the teachers who want to develop the knowledge basis described here,  
41  
42 because personal meaning making is not simply a matter of accepting facts and logical  
43  
44 relationships. It helps to develop an identity by reflecting on one's system of beliefs and values, and  
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46 is also based on the understanding that science is a part of larger communities and their cultures  
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48 (Lemke, 2001).  
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1 The fact that some clients experienced no support from rational considerations is in line with  
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3 the findings of earlier research. For instance, some research has indicated that scientific information  
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5 was either not understood or found irrelevant in dilemmatic situations (Dawson, 2003; Haidt, 2001;  
6  
7 Layton, Jenkins, Macgill, & Davey, 1993). This makes teaching in context an even greater  
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9 challenge, one that surpasses the content perspective of teaching. It raises the question how people  
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11 reason in dilemmatic situations, and whether reflection on that reasoning during their educational  
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13 years can improve it.

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17 Not only are the concepts in the formal curriculum relevant for teaching in context but so are  
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19 additional concepts. This shows the importance of updating school curricula according to changes  
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21 in the field (Table 2). Since our results indicate that teaching based on authentic practices could lead  
22  
23 to a rethinking of curricula, initiatives should be taken to update science curricula in light of recent  
24  
25 techno-scientific developments, such as new knowledge and technologies in genomics, and their  
26  
27 implications for citizens. The first steps on this road have already been made (e.g. Boerwinkel,  
28  
29 Verhoeff, & Waarlo, 2008; Dougherty, 2009).

30  
31 For improving teacher knowledge, the four layers of knowledge of the authentic practice should  
32  
33 be taken into account (Figure 1) in teacher education programmes and the training of biology  
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35 teachers. (Student) teachers need to acquire knowledge of the ELSA and the four-stage-process of  
36  
37 testing helps them in doing so. Next, they require more knowledge of how concepts and ELSA can  
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39 be conceived in the context of specific genetic test situations. Finally, they require knowledge of the  
40  
41 four basic characteristics of genetic practice that make it so challenging.

42  
43 This article has described the content knowledge, part of the necessary knowledge for teaching  
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45 genetics in context. This raises questions about the other categories of teacher knowledge, in  
46  
47 particular the PCK of teaching genetics in this genetic testing practice. Having described the  
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49 concept knowledge for teaching genetics in the context of genetic testing, the question arises how  
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1 this knowledge can be taught (Shulman, 1987). What teaching and learning activities are  
2 appropriate? This is an important question for future research.  
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4

5 In particular, we raised the question how people reason in dilemmatic situations, and whether  
6 reflection on that reasoning during their educational years can improve it. Owing to the moral  
7 aspect of the dilemmatic genetic test situations this kind of reasoning can be referred to as moral  
8 reasoning (Haidt, 2001), and our question indicates that it can be useful to develop teaching and  
9 learning activities for moral reasoning in science education. Although some research has already  
10 been dedicated to this question (Van der Zande, Brekelmans, Vermunt, & Waarlo, 2009), more  
11 research is needed before teachers at different levels in secondary education can be accommodated  
12 with satisfying learning activities for (reflection on) moral reasoning.  
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23 *Respondents of the Educational Practice and the Clinical Genetic Practice*

24 Teachers Bt1 to Bt9, clients C1 to C4, physicians (and genetic counsellors) P1 to P4, and medical  
25 ethicists Me1 to Me4.  
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## 30 Literature

31 Insert Box 2 about here  
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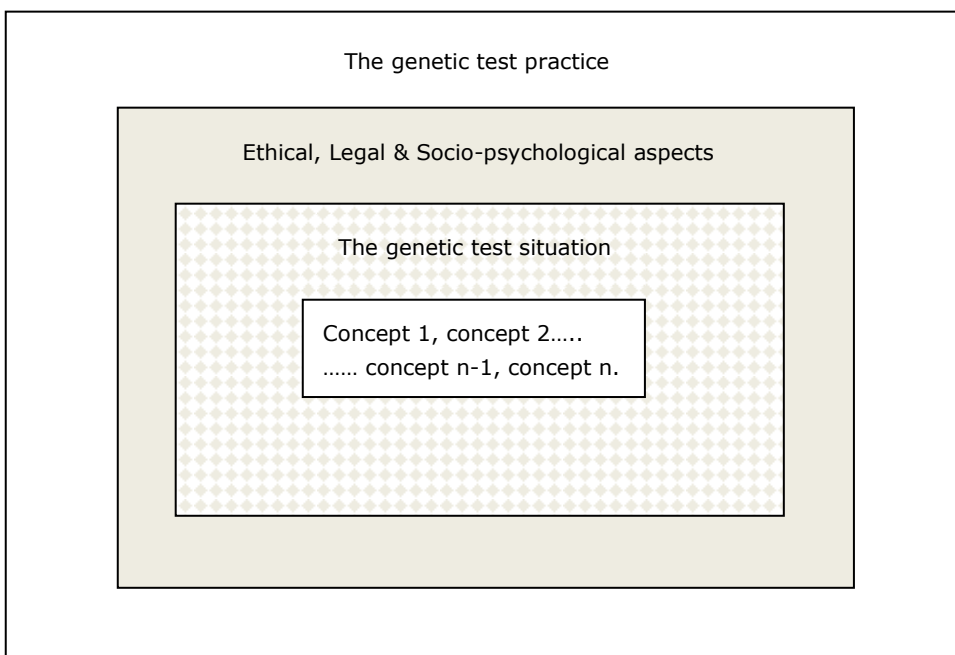


Figure 1. Different layers involved in the genetic test practice.

Table 1. Coding: Exemplary codes with the corresponding utterances from the referents.

Examples of codes	Exemplary utterances using 23 of the original 267 quotations.	Source referent
<b>Main Codes</b>	<b>Concepts</b> CC: Q1 & Q2	
Sub Codes level 1	<i>'I use a standard method ... where the Mendelian genetics is completely covered, with Punnett squares and family trees and all that ... and we link it to the molecular genetics in the higher classes ... they construct the double helix of DNA with paper symbols of the different bases and via all the different steps such as messenger RNA they build proteins'</i>	T1
○ Sub codes, level 2		
Sub codes, level 3	<i>'Some clients lack knowledge or understanding. They ask, for example, "what are those chromosomes?" or "DNA what is that, you can't even see it?" Often they can't believe that this "invisible" DNA determines so much'</i>	P1
<b>C = Concepts</b>	CNC: Q3 & Q4	
CC = Concepts Curricular	<i>'.. I also discuss cytoplasmatic factors, I start with epigenetic factors, it is fascinating to tell about ....'</i>	T2
CNC = Concepts None Curricular	<i>'...I think students have to understand the usual concepts such as dominant - recessive, but also the polygenetic setting .... and the whole genome screening, I think they will be confronted with it within 10 years and then they must understand high and low risk genes ... if they only understand the black or white Mendelian genetics, they cannot understand the complexity of most genetic diseases'</i>	P2
<b>ELSA</b>	<b>ELSA</b>	
E = Ethical	E-V-Pr: Q5	
○ E-V = Values & moral principles	<i>'Concerning technical possibilities like genetic testing, you have to think about the criterion of desirability and the criterion of carefulness. We must reflect on the question whether it is desirable or not to have genetic testing at all. What does it tell us about illness and pregnancy? Are these still natural processes? But you must not think that you can stop these developments. So, it is important to discuss the circumstances under which these tests may be done'</i>	Me1
E-V-A = Autonomy		
E-V-B = Beneficence		
E-V-I = Informed consent		
E-V-J = Justice		
E-V-NM = Non maleficence	E-D-T/NT: Q6	
E-V-P = Privacy	<i>'Imagine you find out that you have a genetic disorder, what can you do? If you cannot prevent or cure it at all, a very important consideration for a doctor is: "do I want to expose my patient to a medical examination when it will bring nothing, just the information that something terrible is bound to happen and you cannot do anything to prevent it?" For the patient the question is whether he or she wants to participate in a process when nothing can be done about it?'</i>	Me2
E-V-Pr = Protectability		
E-V-PV = Prima facie values	E-D-B/NM: Q7	
○ PW = Protecting the weak	<i>'For most expectant mothers it's a big problem, dilemma, if she knows her baby has a genetic disorder. "May I bring this upon my child, what is my responsibility as future parent? Don't we have the responsibility to save them from this misery?" They have to balance this with the felt responsibility of care for their future child. The idea that many women end their pregnancy for trivial reasons is a fable; the vast majority of them experience this as an emotionally difficult dilemma'</i>	Me3
E-V-S = Solidarity		
○ E-D = Dilemma	E-D-T: Q8	
E-D-A/Q = Autonomy - Guilt	<i>'Suppose you decide to abort your child, you can never undo that. You will live the rest of your life with the knowledge that you have aborted a child on genetic grounds. Suppose you do not abort it. Then you have a comparable situation; you have to live with the fact that a child is born that will probably require help and care the rest of its life. After a test, in a timeframe of two weeks you'll have to decide something that impacts the rest of your life. I think that is far too radical. I think that in your adolescence, you have to be trained to deal with this kind of dilemmas. These vital questions cannot be postponed to the moment you are confronted with them'</i>	Me4
E-D-T/NT Treatment or not		
E-D-B/NM care - avoiding harm	E-D-A/Q: Q9	
E-D-T: Time dilemma	<i>'With the introduction of patient autonomy they also became responsible for their decisions, although they cannot know all the consequences... imagine they choose a certain treatment and they become even more sick, than it they are also guilty themselves, so autonomy, becomes responsibility and can become guilt'</i>	Me4
<b>L = Legal</b>	S-F: Q10 & Q11	
○ L-La = Law	<i>'When I finally realised that before they could allow me to do a test, they wanted to involve my brother in the process, I didn't persist, I could not bother him with my problems'</i>	C1
L-LA-NK = Right not to know		
○ L-Lo = Loans	<i>'Sometimes, when a client realises that involvement of family members is necessary, they shy away, e.g. because they don't know these distant relatives or think that they can't burden them with these problems'</i>	P1
○ L-I = Insurances		
S = Socio-psychological	S-ADR: Q12 & Q13	
○ S-F = consequences for family	<i>'... it is the phenomenon that people probably accept e.g. a prenatal test more easy to avoid that they have to say in the future... if we only ...'</i>	Me4
○ S-ADR = Anticipating Decision Regret	<i>'Research indicates that people accept prenatal diagnosis because of what we call anticipating decision regret. They don't want to run the risk of blaming themselves afterwards for not having done everything that's possible to avoid the future misery of their children'</i>	Me1
<b>Ch = Characteristics</b>		
Ch-U = Uncertainty		
Ch-C = Complexity		
CH-P = Probability		
Ch-M = Morality		
<b>O = Other (Remaining codes)</b>		
○ O-D = Disability rights		
○ O-EA = Expressive aspect		

**Characteristics**

CH – C/U: Q14

*'I think that everybody has to understand that, when one nucleotide in your DNA changes, that does not always indicate that you will become ill, but that it adds a little to the risk you are running. And that such a change only leads to trouble when for instance you also get a virus infection. Students have to understand the genome variation and must be able to accept the complexity, the uncertainty and the relative certainty'*

P2

CH-U: Q15

*'Students should be confronted with the limitations. They must be aware that you cannot explain everything with genetics. Biology lessons in a societal context should make them think about what you can do with knowledge, and what you want to do with knowledge. Personally, as well as socially. You can't always get what you want. What are the possibilities? We are bound to laws. We are bound to the possibility to trace a genetic predisposition. If it is a low risk gene and the medical test is expensive, then such a test will not be offered to the client. Some clients find this difficult to accept, they want everything written on paper. They end up by visiting websites where all kinds of tests are being offered. I think education can help people to become informed about what you can learn from these tests. What is certain, what can be proved for sure, and what is information that won't help you at all?'*

P1

CH-P: Q16

*'It is a chance, but for each human being it is 'yes' or 'no', and that's what they want to know'*

P3

CH-M: Q17 &amp; Q18

*'Although we have these four principles, e.g. autonomy and justice, I think it is very important to relativise that. It is also very important that we learn how to reflect on a situation in a personal way, that you realise that a situation is always much more complex than it seems at first glance, that you realise how you intuitively would like to act in a situation and that you are willing to reflect on this intuition, this preconceived opinion ... it is important to teach our students that uncertainty is a great value, because this 'not knowing' gives you the opportunity and the time to grasp the complexity of these dilemma's'*

Me4

*'How to deal with all this information, how to deal with all the advice you get from the people around you, how to reflect on your first intuitive reactions, I think that is the most important goal of education'*

P3

CH-C: Q19, Q20 &amp; Q21

*'Although my wife is working in the healthcare and I am a biologist, at the moment we were confronted with the fact that our child had Down syndrome, this knowledge had no use. At that moment we were confronted by different emotions and moral questions. Biomedical knowledge didn't help us at all'*

C2

*'I felt all kinds of emotions, I was frightened. There was chaos in my head: what do I have to do now? I thought: "help, I know nothing about this". And all the people I esteem highly, gave me different advice, it was very confusing'*

C4

*'They must understand the difference between disposition for a disease and getting a disease. Or the difference between having the disposition and being a carrier'*

P3

O-D/EA: Q22 &amp; Q23

*'Are we going to protect the weak and the vulnerable? Whose responsibility is that, the client's, the doctor's or of society as a whole? And how is this responsibility related to the principle of the autonomous patient?'*

Me2

*'When you think about the status or respectability of a foetus, you have to deal with the disability rights criticism. Disabled people, or those closely related, find themselves discriminated by these kinds of questions'*

Me3



Table 2. List of biological concepts for genetics education in the health context of genetic testing, in the extended CVBO matrix (Boersma et al., 2007).

Levels of biological organisation	System concepts				
	Biological unit	Self regulation and self organisation	Interaction	Reproduction	Evolution
<b>Molecular</b>	Adenine (A) Allele Amino acids Base Cytosine (C) DNA Gene Guanine (G) Nucleotide Protein RNA Thymine (T) Uracil (U)	Base pair Base sequence Double helix	Dominant <b>High/low risk gene</b> Recessive <b>Single nucleotide polymorphism (Snip)</b>		<b>Genetic polymorphism</b> Mutation
<b>Cellular</b>	Autosome Chromosome Genome Sex chromosome X chromosome Y chromosome	Genetic code Mitosis Cancer		Diploid Haploid Heterozygote Homozygote Meiosis	
<b>Organ system</b>		Cancer			
<b>Organism</b>		Cancer	<b>Multifactorial disorder</b> <b>Polygenic disorder</b>		Chance
<b>Population</b>				Mendelian inheritance Pedigree	<b>Genomic variation</b>
<b>Ecosystem</b>					
<b>Biosphere</b>					
<b>Context concepts</b> (Domain specific techniques and activities)	<b>Sequencing, genetic testing, micro-array, whole genome screening, risk assessment</b>				

(**Bold** are the concepts mentioned by the referents from the authentic genetic testing practice, which are not (yet) included in the Dutch biology examination syllabus)

Box 1. Concepts, ELSA, and characteristics of the genetic test practice illustrated by a client story.

### The story of Anne

Looking back on it now, I realize that I did those tests, the Triple test, without proper considerations in advance. All I really wanted was reassurance. And of course that is a strange starting point, because there is a chance that you won't be reassured. I think that most people doing punctures and other such tests expect to be reassured and ready to enjoy their pregnancy afterwards. For me this was a naïve way to view such a test. Especially a test that will only give you a chance, a percentage. Because then in fact you still know nothing. I would never do that test again. If I ever was to feel the need for such a test I would do a puncture or some other test that would give me more certainty. And I would have thought about what I would do with the possible results in advance, so I would be able to anticipate on them. After John, who could not even walk though he was three, my mistake was that I thought I could not handle another child with a handicap. I thought I could not endure another infant who could not do anything on his own. So I decided to get myself some reassurance. And although the echo looked ok, I was worried, so I did a test that was not risky for the baby. You are so relieved that something can be done, so you do it, because you don't want to feel like you didn't do everything possible for your child. When my husband got the phone call and the doctor told him that I had a risk of one out of 280 or something, my husband responded with: "well that sounds good". But it was not good at all! It was an increased risk, and I should visit the doctor. He told me that my risk was four times higher than normal, and suddenly it sounded completely different. One out of 280 or four times higher than normal. But in the mean time I was pregnant for 13 or 14 weeks. The triple test indicated it wise to puncture my placenta. That tests' outcome could be expected within one or two weeks and then I had exactly one week left to decide whether I wanted an abortion or not. How could I decide in two weeks time over the life or death of my child? I was just in time and could "still do something about it" as the doctor put it. But my body already showed my pregnancy, and I felt life inside me, little movements. So I looked down at my belly and thought; doing something about it? No way, it's my baby. I felt so unhappy, I didn't want that puncture, in fact I only wanted to tuck it all away. If they had told me I had a chance of 50 percent, maybe. But even then I didn't want to make that kind of decision, I didn't want to decide for an abortion, because I was afraid I would regret it in the end. On the other hand, I know it could mean a lot of special care. And I am not religious in the way that I believed this to be the burden I had to carry. I did not think I could manage it without depriving my other two kids, my family. The doctor strongly advised me to do the puncture and was looking very worrisome. So I came home crying and told my husband I had a chance of one out of 280. And he responded: 'what kind of a chance is that anyhow? If you step out the front door, you might have the same chance to get hit by a car.' Later we saw on the internet that a puncture had the same chance of miscarriage, so what kind of choice was this? I was so confused, so unprepared. When you have a healthy child with Down syndrome, it can still live a happy life. However, if it has to undergo all kinds of operations, and it would suffer a lot, what kind of life would that be? And until today, it is still not clear to me what a chance of one out of 280 actually means. 'Chance' wasn't just flowing in my bloodstream, was it? There must have been something in my blood that was not good, but they never explained it to me. Either there was something in my blood or something wasn't in my blood, but there is no 'chance' in it. As lay person I did not get it. Fortunately I went to my midwife and she soothed me. We should have seen something on the echo. Also my mother convinced me that our baby would be just fine and that I should trust my own body and feelings. And you know, there are always risks, you have to accept that. From that moment on, I pushed it away until the birth of Joan. And although I pushed it away successfully, the relief was immense when everything turned out to be right when she was born. I never went back to that doctor again, I was so angry at him, at the situation, at myself, for being so naïve. The doctor never told me what an acceptable chance was, or when it would be wise to do a puncture or not. He simply advised me just to do the test first and then we would see what's next. Now I know that's not wise. You should think about what you would want to do with every possible outcome. People should know whether they want to know it, why they want to know it, and what they would do if they knew it. In the end I chose that I didn't want to know, in good faith and hoping for the best.

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Box 2. Books and articles (for the saturation strategy concerning the ELSA of medical decision-making).

1. (Bates, 2003)
2. (Beauchamp & Childress, 2001)
3. (Bolt, Verweij, & Van Delden, 2005)
4. (Borkenhagen et al., 2007)
5. (Challen, Harris, Benjamin, & Harris, 2006)
6. (Cherry & Cherry, 2003)
7. (Collins, Green, Guttmacher, & Guyer, 2003)
8. (De Visser, 2007)
9. (De Wert, 1999)
10. (Decruyenaere, 2003)
11. (Dols-Caenen, Konings, Gómez Garcia, & Schrande-Stumpel, 2008)
12. (Finck, Meister, Stöbel-Richter, Borkenhagen, & Brähler, 2006)
13. (Frets, 1990)
14. (Grient Dreux, Kooijman, & Korenromp, 2008)
15. (Grob, 2006)
16. (Guttmacher, Porteous, & McInerney, 2007)
17. (Harvey et al., 2007)
18. (Hietala et al., 1995)
19. (Nyrhinen, Leino-Kilpi, & Hietala, 2004)
20. (Nyrhinen, Hietala, Puukka, & Leino-Kilpi, 2007)
21. (Pin & Gutteling, 2005)
22. (Resnik, 2003)
23. (Rosner, 2004)
24. (Rowley, 2007)
25. (Rudnick, 2007)
26. (Stratton & Rahman, 2008)
27. (Twomey, 2006)
28. (Vähäkangas, 2001)
29. (Van Baarsen, 2003)
30. (Van Kleffens, Van Baarsen, & Van Leeuwen, 2004)
31. (Van Neste, 1993)
32. (Wilfond, 1995)
33. (Wüstner & Heinze, 2007)
34. (Yesley, 2008)
35. (Zallen, 1997)