

# Global Application of the Assessment of Communication Skills of Paediatric Endocrinology Fellows in the Management of Differences in Sex Development Using the ESPE E-Learning.Org Portal

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## Keywords

Online learning · E-learning · Subspecialty training · Disorders of sex development · Congenital adrenal hyperplasia · Competency assessment

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## Abstract

**Background:** Information sharing in chronic conditions such as disorders of/differences in sex development (DSD) is essential for a comprehensive understanding by parents and patients. We report on a qualitative analysis of communication skills of fellows undergoing training in paediatric endocrinology. Guidelines are created for the assessment of communication between health professionals and individuals with DSD and their parents. **Methods:** Paediatric endocrinol-

ogy fellows worldwide were invited to study two interactive online cases ([www.espe-elearning.org](http://www.espe-elearning.org)) and to describe a best practice communication with (i) the parents of a newborn with congenital adrenal hyperplasia and (ii) a young woman with 46,XY gonadal dysgenesis. The replies were analysed regarding completeness, quality, and evidence of empathy. Guidelines for structured assessment of responses were developed by 22 senior paediatric endocrinologists worldwide who assessed 10 selected replies. Consensus of assessors was established and the evaluation guidelines were created. **Results:** The replies of the fellows showed considerable variation in completeness, quality of wording, and evidence of empathy. Many relevant aspects of competent clinical communication were not mentioned; 15% (case 1) and 17% (case 2) of the replies were considered poor/insufficient. There was also marked variation between 17 senior experts in the application of the guidelines to assess communication skills. The guidelines were then adjusted to a 3-level assessment with empathy as a separate key item to better reflect the qualitative differences in the replies and for simplicity of use by evaluators. **Conclusions:** E-learning can play an important role in assessing communication skills. A practical tool is provided to assess how information is shared with patients with DSD and their families and should be refined by all stakeholders, notably interdisciplinary health professionals and patient representatives.

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## Introduction

Delivery of optimal clinical care should be patient- and family-centred. A comprehensive understanding by parents and patients of a chronic condition such as disorders of/differences in sex development (DSD) is a necessary prerequisite for ongoing communication and care [1–4]. The objectives of information sharing are multiple: first, it allows the parents and patient to understand the condition with all its short- and long-term implications for management; second, it supports the psychological adaptation required to live well with the condition; and finally, it enables communication within the patient's social environment [4]. All these factors will impact positively on the quality of decisions made by patients and families, and adherence to the demands of ongoing management.

Information sharing in DSD conditions is particularly challenging since not only is the management of individuals with DSD continually evolving, it is also taking place within the context of changing perceptions of sex and gender, with questioning or rejection of the binary nature

of both constructs in parallel with corresponding changes in societal regulations [5, 6]. Communicating DSD information requires navigating difficult subjects, such as the stigma anticipated by the parents or patient, sensitive matters including potential future sexual activity or fertility, and perhaps most challenging, awareness of one's own tendencies to perpetuate cultural norms that might oppress or limit an individual with a DSD and negatively affect their developing identity.

The rather complicated information on genital development and puberty should be provided to patients in clear and understandable terms. If the information is explained incompletely or deferred, there is a risk of inaccurate self-diagnosis without the opportunity for discussion with expert care providers [7]. Moreover, it has recently been suggested that the confusion parents of children with a DSD feel regarding the information on their child's condition may lead to the development of posttraumatic stress syndrome [8].

Paediatricians pursuing subspecialty training in paediatric endocrinology (fellows) are taught that the conversations with parents and the patient should be informative, but non-intimidating and sensitive to discomfort and anxiety. These conversations should also be respectful of cultural and psychosexual issues [5].

In a recent paper, we reported results of an exploratory study regarding the suitability of the European Society of Paediatric Endocrinology (ESPE) e-learning portal to assess, at a global level, junior paediatricians (fellows) during their subspecialty paediatric endocrinology training regarding knowledge and skills for investigation and management of children and adolescents with DSD [9]. An additional objective of this study was to evaluate the communication skills in informing patients and parents about the diagnosis and management. So far, there have been various examples of the suitability of e-learning in medical education. The review by Sinclair et al. [10] suggests that e-learning is at least as effective as traditional learning in improving health care professional behaviour. There are some examples of e-learning modules especially dedicated to the improvement of patient-physician communication skills [11–13]. The intent of this study was to explore whether the communication skills could be assessed and taught in a formative way in an online environment – in particular, to learn from online feedback. So far, no other such study has been described.

Here we report on the qualitative analysis of these communication skills, including addressing of key elements in the information-sharing process, with particular emphasis on wording and empathy. In presenting these

materials, we also create guidelines for the assessment and teaching of communication between health professionals and parents of newborns and individuals who have a DSD.

## Material and Methods

The outline of the study has been described previously [9]. In brief, paediatric endocrinologists in training worldwide (referred to hereafter as fellows) were invited to login to a specially created DSD e-learning course within the ESPE e-learning portal ([www.espe-elearning.org](http://www.espe-elearning.org)). Access was provided to two interactive DSD cases prepared as e-learning exercises in English. The two clinical cases were within the expertise of paediatric endocrinologists; the fellow was asked to play the role of a paediatric endocrinologist in an interdisciplinary DSD team.

Case 1 focused on the stepwise approach to the investigation and management of a newborn referred by a midwife because of atypical genital development secondary to congenital adrenal hyperplasia (CAH). Case 2 addressed the approach to a 17-year-old girl with delayed menarche due to 46,XY gonadal dysgenesis. At crucial stages of the diagnostic process, 3 open-ended questions (i.e., requiring a text response) were included, in which the fellow was invited to describe how (s)he would handle the situation, focusing on how (s)he would inform the parents and/or patient of key information regarding diagnosis, implications and management. The fellows had received no formal training in communication skills over the course of their fellowships.

The replies to the open-ended questions of each fellow were submitted to 2–3 senior paediatric endocrinologists (referred to hereafter as experts) from various parts of the world. At least 1 of the experts worked in the same geographic region as the fellow (excluding the expert at the institution where the fellow was employed). The experts were invited to reply with feedback to the fellows' replies. The experts were provided with an exemplary model answer prepared by the study team, which they were free to use. For each question, key items were identified as critical elements of an adequate reply by the study team. Subsequently, the fellows were asked to acknowledge and reply to the comments of the experts. All procedures were handled anonymously through the e-learning portal.

The present study focused on open question 2 of case 1 and open question 1 of case 2, reflecting communication skills in the field of DSD. A description of the cases and selected questions is provided in Table 1. There appeared to be a wide variation in the replies of the fellows, not only in the number of key items mentioned, but also in the quality of the wording and in the use of empathy. Therefore, to evaluate all the replies, there was a strong need for a structured approach and a rubric was developed. Rubrics are documents that articulate the expectations for an assignment by listing the assessment criteria and defining levels of quality in relation to each of these criteria. The steps below describe this process, which is also presented in a flow chart shown in Figure 1.

### Step 1 – Development of Guidelines for Assessment

First (step 1a), the replies of the fellows were dissected into sentences relating to the identified key items. All passages were analysed by one person (S.L.S. Drop), who rated the passages on a scale

of 5 levels (poor-insufficient-reasonable-good-excellent). According to this analysis, descriptors were defined. Descriptors spell out for each key item at each level of performance what performance at that particular level looks like. This resulted in a rubric, providing objective guidelines for the assessment of the fellows' replies. In the next step (step 1b), these guidelines were provided to the study team for discussion. The study team consisted of paediatric endocrinologists, psychologists, educationalists and patient/parent representatives (S.L.S. Drop, M. Cools, J. Alderson, L.J.C. Kranenburg, K. Grijpink, M. Muscarella, E. Magrite). After extensive adjustments, consensus was reached (online suppl. Table 1; see [www.karger.com/doi/10.1159/000475992](http://www.karger.com/doi/10.1159/000475992) for all online suppl. material).

### Step 2 – Testing of the Guidelines for Assessment

To validate the guidelines, a selection of the answers from 10 fellows to the open questions of each case was made, based on the first evaluation by one of the investigators. The selection represented a representative sample of all received replies. The selected replies for cases 1 and 2 were not necessarily from the same fellow. The sentences in the replies were cut into passages and grouped according to the identified key items. Twenty-two senior paediatric endocrinologists worldwide (referred to hereafter as assessors) were invited to participate. They were provided access to an online questionnaire with an overview of the two cases and the two open questions (Table 1), the selected replies (provided as distinct passages), and a link to the study design and the guidelines (online suppl. Table 1). Assessors were asked to score each of the passages based on the provided guidelines on a 5-point scale from poor to excellent. To assess the complete reply, assessors were also asked to score the total number of key items described correctly in the answer, and to score the overall reply on a 5-point scale from poor to excellent, taking into account completeness, quality of the answer, and the use of empathy.

### Step 3 – Evaluation of the Guidelines for Assessment

As this study aimed to create globally applicable guidelines, one assessor with minimal intra-observer variability compared with the other assessors was identified as an outlier and excluded from further evaluation. Assessors who did not complete all replies were also excluded. The scoring of the remaining assessors was evaluated for each key item separately, as well as combined together as an overall assessment, using an intraclass correlation coefficient (ICC). For further details, see the statistics section. This resulted in an evaluation of the interobserver variance for the assessment of the separate key items and the overall assessment. This analysis was first performed using a 5-level rating (poor-insufficient-reasonable-good-excellent) and subsequently using a 3-level rating (poor-reasonable-good). For the 3-level rating, the two lowest levels (poor and insufficient) and the two highest levels (good and excellent) were combined.

To measure the agreement between the assessors of the competency score of the separate text passages, we calculated the standard deviation for the score of the assessment (1 poor – 5 excellent) of (i) the separate text passages and (ii) the overall reply. The standard deviation was used to identify text passages with a high level of agreement/low standard deviation and passages with a low level of agreement/high standard deviation. These text passages were studied in detail, taking into account the geographic background of the assessors and the provided comments.

**Table 1.** The cases and the open questions as provided to the fellows

Case 1 – CAH

Mrs. Johnson is at home and has just given birth to her second child. Her pregnancy was uncomplicated, and her term delivery was uneventful. The infant has a birth weight of 2,940 g, and had an Apgar score of 9/10. The midwife is very concerned about the infant's genital development, as it is unclear to her whether the child is a boy or a girl. The decision is made to transfer the baby to a specialized centre. You are now the paediatric endocrine fellow in charge.

Physical examination of the infant at 4 h of age reveals a healthy looking, well-developed, alert, non-dysmorphic newborn. The infant is not in any distress. The baby's genitalia have the following features: the hyperpigmented labio-scrotal folds are fused posteriorly; the gonads are not palpable; the phallic structure is tethered by a fibrous string (chordee); there is one opening on the perineum through which urine is passed.

**Open question provided to the fellows**

Based on laboratory and imaging studies you have just made the diagnosis of congenital adrenal hyperplasia (CAH), most likely as a result of 21-hydroxylase deficiency.

Give a detailed account of how you will inform the parents of the diagnosis. Consider the following elements: the setting; allotted time; explanation of the diagnosis; therapeutic issues; implications for later; follow-up; other considerations.

Case 2 – Gonadal dysgenesis

Ranya, a 17-year-old girl adopted from Sri Lanka, is referred to you because of delayed puberty. She is quite concerned, as she hasn't had her period yet, whereas all her girlfriends are menstruating. She saw a doctor 2 years ago because of delayed breast development, and the doctor told her just to be patient.

Ranya was born at term with a birth weight of 2,400 g; her length was not measured at birth. She was adopted at the age of 6 weeks. No family history is available. At the age of 14 weeks, she was diagnosed with viral meningitis without obvious sequelae. Since then, she has been healthy and takes no chronic medications. Her developmental milestones have been normal. She noticed some pubic hair growth at 12 years of age, but no breast development, and menarche never occurred.

**Open question provided to the fellows**

Based on laboratory and imaging studies you have made the diagnosis 46,XY gonadal dysgenesis.

Give a detailed account of how you will arrange the sharing of information to Ranya and her parents. Consider the following elements: the setting; allotted time; key items to be discussed regarding the diagnosis; relevant therapeutic issues; long-term implications; follow-up; other considerations.

In addition, describe how you will address Ranya and her parents when informing them about the diagnosis and therapeutic options.

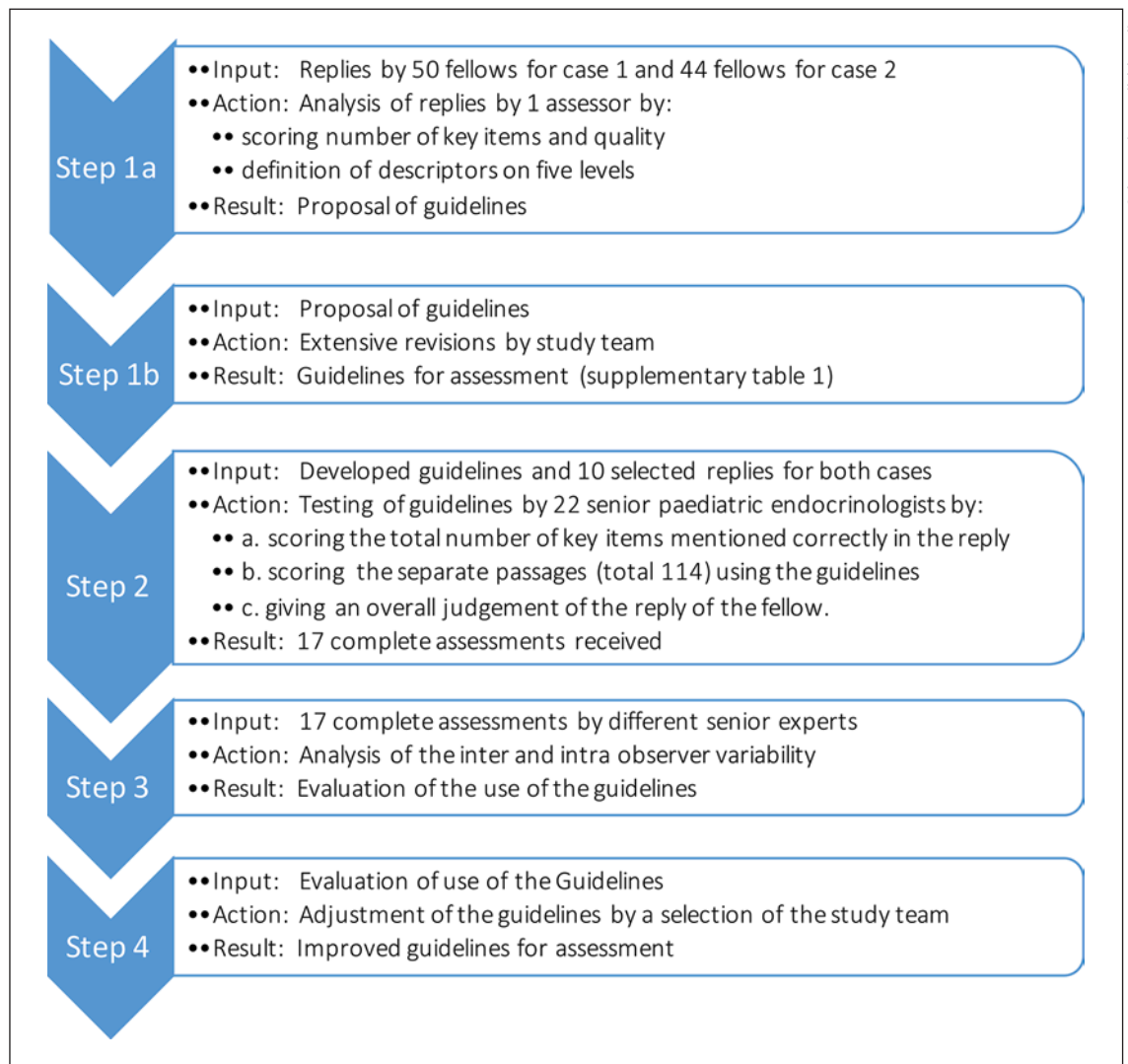
This information was also provided to the assessors in the online questionnaire in order to mark the selected answers of the fellows on these questions.

*Step 4 – Adjustment of the Guidelines for Assessment*

The above analyses were used to adjust, where necessary, the guidelines for communication to parents of newborns with CAH and for girls and young women with gonadal dysgenesis. The number of key items was evaluated and optimized, as were the number of levels describing the performance of the key items, in order to create the final guidelines.

*Statistical Analysis*

To determine the level of agreement between assessors represented by the interrater reliability (IRR), an ICC(2,k) statistical analysis was performed ("icc" command from "irr" package for R, settings: model = "twoway", type = "agreement", unit = "single"). All analyses were performed using R (version 3.2.2, R foundation for Statistical Computing, Vienna, Austria). A *p* value  $\leq 0.05$  was used as a cut-off for statistical significance.



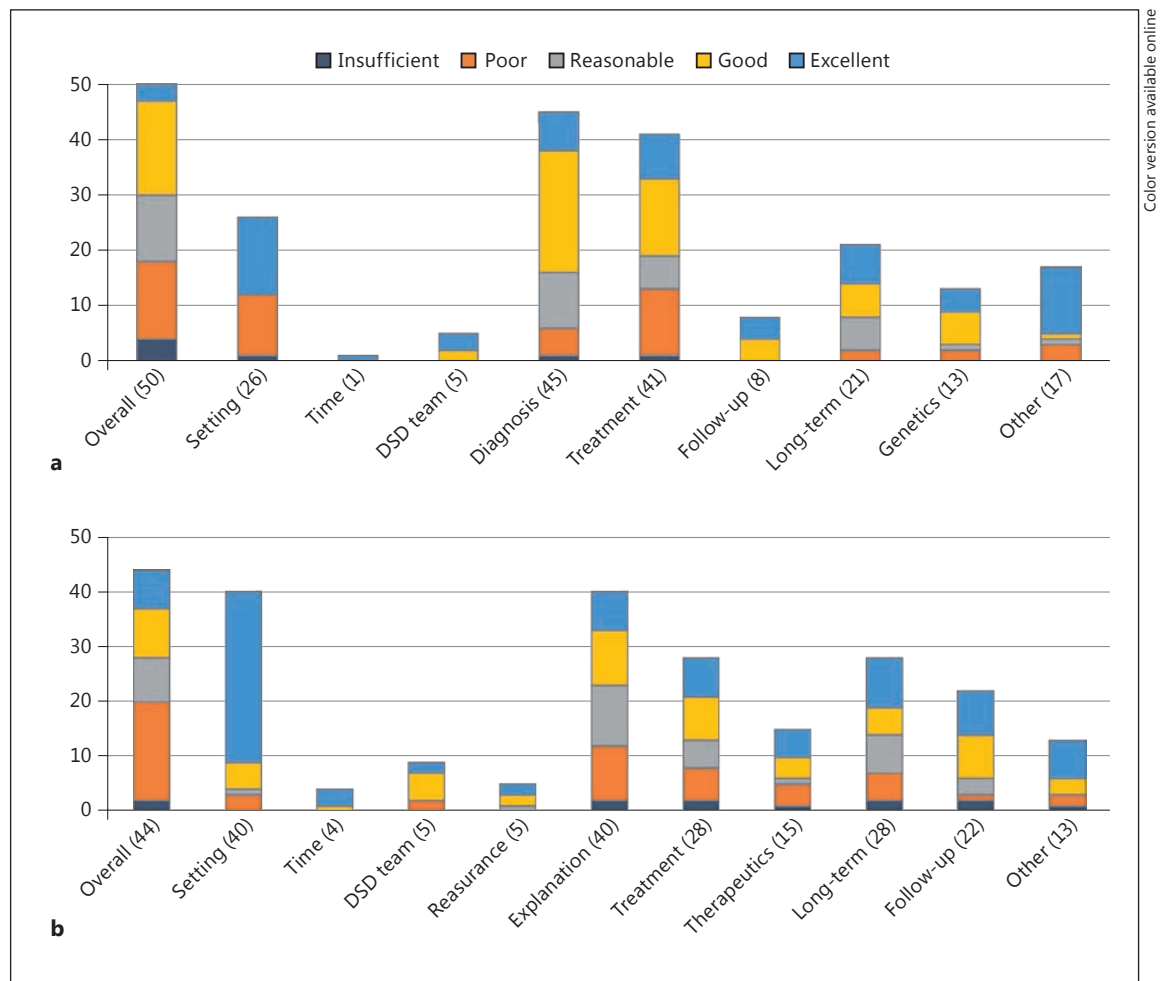
**Fig. 1.** Flow chart describing the steps in development, evaluation and adjustment of the guidelines for assessment of communication skills in DSD. The steps are described in detail in the methods section.

## Results

### *Step 1 – Development of Guidelines for Assessment*

Fifty fellows responded to the open question for case 1 and 44 fellows to the open question for case 2. The global distribution of the participating fellows has been previously described [9]. As described in the methods section, these replies were analysed by scoring the number and quality of the predefined key items on a 5-level rating scale. The results for both cases are presented in Figure 2. We found that there was substantial variation not only in the number of key items mentioned, but also in the quality of the responses. Examples of text phrases that quali-

fied for the different rating categories are presented in online supplementary Table 2. From this analysis, descriptors were defined, which described each key item at all levels of performance. This allowed the creation of guidelines to score (into 5 categories) the fellow’s explanations of the 2 conditions for accurateness, clarity, and empathy. These guidelines were then passed to the study team for refinement and consensus. The resulting product was the guidelines used in this study for assessing communication with parents of newborns with CAH and with girls with complete gonadal dysgenesis (online suppl. Table 1).



**Fig. 2.** The vertical axis represents the number of replies by the fellows and the frequency with which the different key items were identified in the reply for case 1 (top) and case 2 (bottom). The horizontal axis shows the overall judgement and the identified key items (number of assessments in brackets). Colours represent the marking on a 5-point scale. This analysis shows that items “diagnosis” and “treatment” are the items most frequently mentioned (45/50 and 41/50 fellows for case 1 and respectively by 40/44 and 28/44 fellows for case 2). “Setting” is mentioned by 26/50 fellows

for case 1 and 40/44 times for case 2. The quality of the text fragments specifying “setting” ranged from “poor,” when no information on the setting was provided, to “excellent,” when the importance of a private ambience was recognized. Remarkably, “allotted time,” explanation of “the role of the DSD team” and the relevance of providing long-term “follow-up” was rarely mentioned. Items mentioned in the category “other” were, for example, handing out written explanations, figures and drawings, and time for questions.

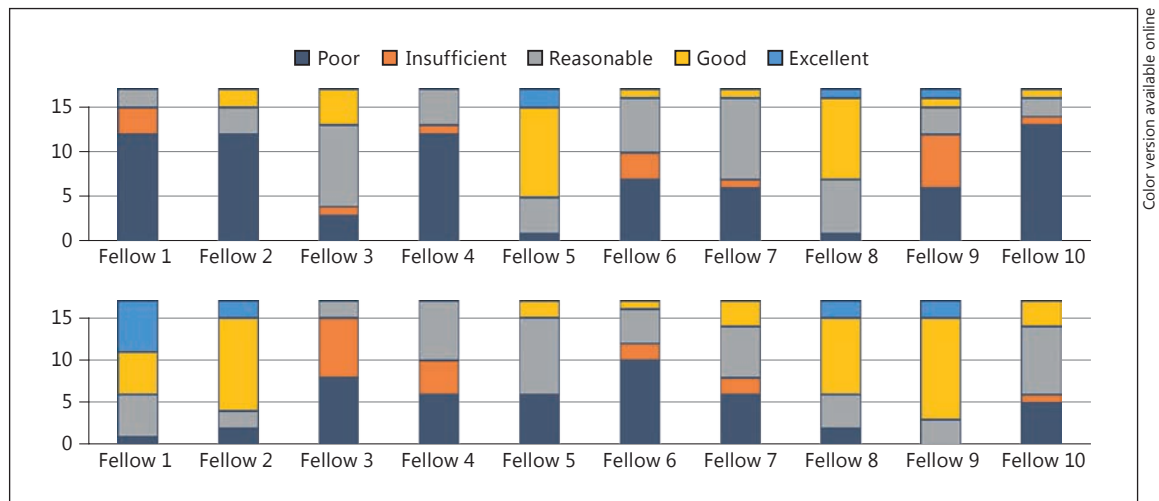
### Step 2 – Testing of the Guidelines for Assessment

We randomly selected the replies of 10 fellows to each of the 2 open questions. These answers were divided into passages according to the defined key items and sent to 22 experts to score, as outlined in the methods. The demographic background of the experts was as follows: Africa (1); Asia (4); Australia (1); Europe (8); North America (5); and South America (2). The interrater variability, the standard deviation and the distribution of the assessment categories are represented in online supplementary

Table 3. We received 21 replies from the experts. Two incomplete replies and 1 which was regarded as an outlier (due to low variation and only high scores in contrast to other experts) were excluded from further evaluation, resulting in 17 complete expert evaluations of the fellows’ replies.

### Step 3 – Evaluation of the Guidelines for Assessment

The assessments of the fellows’ responses by the experts showed considerable interrater variation. As shown



**Fig. 3.** Assessment of the complete answer of the selected fellows by 17 assessors for case 1 (top) and case 2 (bottom). Horizontal axis represents the fellows, vertical axis the number of assessors. Colours indicate the rating. Outliers and incomplete data were excluded. For example, this shows that there was considerable variation in the rating of reply of fellow 9 for case 1 which is rated as: poor, 6 times; insufficient, 6 times; reasonable, 3 times; good, once; and excellent, once.

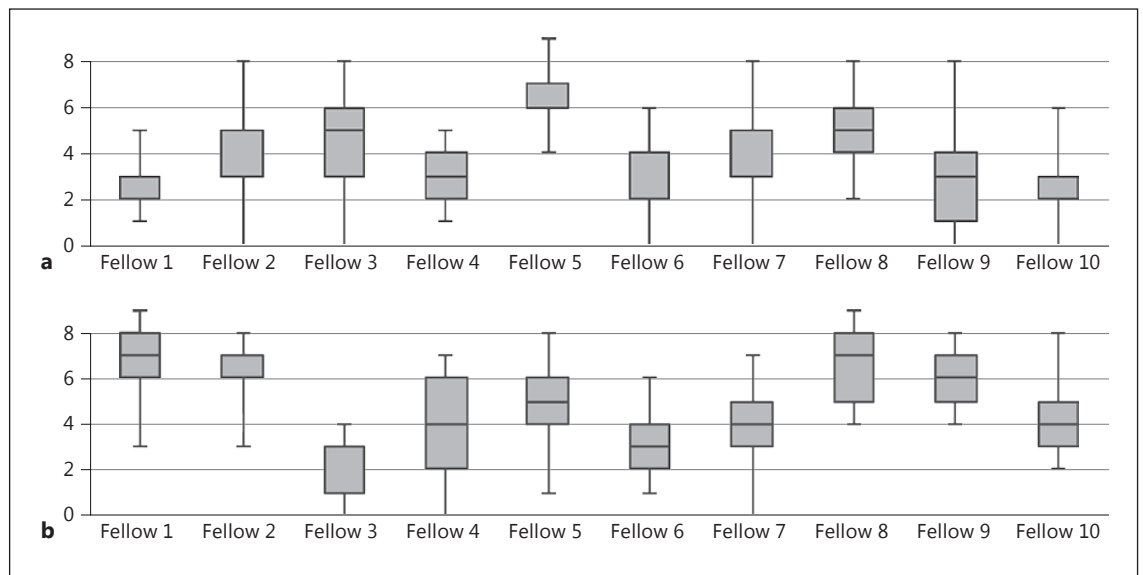
**Table 2.** Intraclass coefficient (ICC) of the ratings provided by the assessors (excluding outliers and incomplete data)

	5-level rating		3-level rating	
	ICC	95% CI	ICC	95% CI
All assessments (134)	0.37	0.31 < ICC <0.45	0.41	0.34 < ICC <0.48
Overall (20)	0.42	0.28 < ICC <0.62	0.47	0.32 < ICC <0.67
Setting (17)	0.58	0.42 < ICC <0.78	0.68*	0.53 < ICC <0.84
Follow up (5)	0.34	0.13 < ICC <0.82	0.38	0.15 < ICC <0.84
Explanation (44)	0.32	0.22 < ICC <0.44	0.35	0.25 < ICC <0.48
Treatment (20)	0.31	0.19 < ICC <0.51	0.31	0.19 < ICC <0.51
Long-term implications (11)	0.28	0.13 < ICC <0.56	0.27	0.13 < ICC <0.56
Genetics (5)	0.23	0.06 < ICC <0.74	0.20	0.05 < ICC <0.71
DSD team (2)	0.12	-0.02 < ICC <0.99	0.11	-0.03 < ICC <0.99
Check understanding (6)	0.09	0.02 < ICC <0.43	0.06	0.008 < ICC <0.35
Other considerations (2)	0.06	-0.01 < ICC <0.99	0.08	-0.006 < ICC <0.99

Parentheses in the first column represent number of responses. The first row represents ICC for all assessments together (ICC 5-level rating 0.37); the second row represents ICC for overall judgement of the replies (ICC 0.42); and the rows following indicate ICC for the ratings of the evaluated text passages referring to the indicated key items. The columns provide ICC values and 95% confidence intervals (CIs) for the used 5-level rating scale and for a 3-level rating scale when the lowest and highest two scores are taken together. When adjusting for a 3-level rating scale by combining ratings “poor” and “insufficient” as the lowest rating and combining “good” and “excellent” as the highest rating. \* The ICC for “setting” is significantly higher than for all assessments together.

in Table 2 using the 5-level rating by the provided guidelines, the ICC for all 134 assessments was 0.37 (95% confidence interval 0.31–0.45), indicating a low level of agreement between the assessors. The highest agreement was

reached on the assessment of passages related to “setting,” with an ICC of 0.58. The ICC on the overall assessment of the complete answer was higher than the assessment of the separate text passages referring to specific key items.



**Fig. 4.** Number of key items correctly mentioned in the replies of the fellows for case 1 (a) and case 2 (b) as scored by 17 assessors, represented in box-and-whisker plots. Horizontal axis represents the separate fellows; vertical axis represents the number of key items. Whiskers represent minimum and maximum values; boxes represent first and third quartiles and the median; outliers and incomplete data were excluded. For example, for fellow 9 of case 1, the minimal number of items mentioned was none, the maximum number of items was 8 and the median was 3.

However, statistical significance was never reached. Some categories such as “the role of the DSD team” or “checking of understanding” were mentioned too infrequently to calculate a reliable ICC. When adjusting for a 3-level rating scale by combining ratings “poor” and “insufficient” in the lowest rating and combining “good” and “excellent” as the highest rating, the ICC for “setting” was significantly higher than for all assessments together.

There was remarkable assessor disagreement in rating the fellows’ replies for both cases, as illustrated in Figure 3, which shows the assessments for the complete replies of each fellow. The numerical rating of correct key items mentioned in the communication/explanation also showed a wide range, as illustrated in Figure 4. Phrases with a high level of rating agreement or a low level of rating agreement were identified, as described in the methods section. Examples of these passages are provided in online supplementary Table 4.

Consensus was reached when answers were very short or blunt, and rated as poor or insufficient. Rating was good or excellent when an answer was complete, mentioning relevant details and expressing empathy. The variation in the ratings by expert assessors was as extensive as the variation in answers provided by respondent

fellows. However, no relationship between assessment rating pattern and demographic background of the assessors could be established.

#### *Step 4 – Adjustment of the Guidelines for Assessment*

Based on these findings, the guidelines were adjusted to a 3-level assessment, with empathy as a separate key item. The revised guidelines better elucidated the qualitative differences in the replies. The final guidelines are presented in Table 3.

## **Discussion**

In this exploratory study, we evaluated the applicability and feasibility at a global level of the ESPE e-learning portal in assessing junior paediatricians (fellows) during their subspecialty paediatric endocrinology training. We examined the quality of communication skills for information sharing with patients with DSD and/or their parents. So far, there has been little experience in the evaluation of formative assessment within the widespread utilization of online learning in the education of medical specialists [14]. However, it has been shown that e-learn-



**Table 3.** Guidelines for the assessment of communication skills

Key item	Good	Reasonable	Insufficient
<i>When informing parents of a newborn with CAH</i>			
Setting	Private room; no interruption by colleagues, personnel etc.; no beepers, mobile phones	Private room; interruption policy not arranged	No privacy provided
Time	Approx. 30–45 min; ensure that parents are aware of the time allotment. If necessary, follow-up in the following days/week	Approx. 30–45 min	Limited time (<15–20 min)
Reassurance	Emphasizing: “Your baby will be fine.” Normal life expectancy; fertility possible	Mentioning: normal life expectancy; fertility possible	Not mentioned
One spokesman on behalf of the DSD team	One spokesman on behalf of the DSD team or jointly with medical team psychologist (if available)	One spokesman on behalf of the DSD team	DSD team not mentioned
Explanation of diagnosis	1. Adrenal disorder termed congenital adrenal hyperplasia, abbreviated as “CAH” with prenatally increased levels of “male-type” hormones, androgens 2. Uterus and ovaries present 3. Shows explanatory pictures or drawings	Relevant items mentioned but limited explanation	Relevant items not or incompletely mentioned
Treatment	1. Corticosteroid treatment (life-long) will stop virilization 2. Salt loss requires fludrocortisone treatment (life-long) 3. Instruction for administration of stress medication	Life-long and stress medication mentioned but with limited explanation	Life-long medication not or incompletely mentioned stress medication not mentioned
Follow-up	Provides information regarding regular follow-up for adjustment of dosage of medication and reminder of instructions for administration of stress medication is essential; discusses importance of adherence to prescribed treatment and consequences of non-adherence	Some but not all items mentioned but limited explanation	Not mentioned
Long-term implications	The clitoris is expected to become less noticeable under medical treatment; joint appointment with surgeon (or urologist or gynaecologist) to check on this in about 3–4 months to discuss whether or not genital surgery is an option	Some but not all items mentioned but limited explanation	Not mentioned
Genetic counselling	Explanation of the genetics of CAH and risk for future pregnancies, also options for pre-implantation genetic diagnosis <i>Note – in some institutions this will be done by a genetics consultant or counselor rather than endocrinologist. Need to raise the issues that must be discussed, and list options for who will undertake this discussion</i>	Genetics mentioned but not explained	Genetics not mentioned
Empathy	<i>Questions:</i> time for parents’ questions and concerns <i>Checks understanding:</i> checks whether the main messages are understood, such as the diagnosis and therapeutic consequences, adjustment of medication dosages, and stress medication <i>Written information:</i> written summary of discussion <i>Arranges meeting with parent/patient:</i> offers to arrange in clinic a meeting with another family who are caring successfully for a child with CAH <i>Reading material:</i> reading materials published by support groups, contact information for local and/or online support groups	Items mentioned in part	Items not mentioned
<i>When informing a patient with gonadal dysgenesis and her parents</i>			
Setting	Make an appointment with patient and both parents; private room; no interruption by colleagues, personnel etc.; no beepers or mobile phones	Private room; interruption policy not arranged	No privacy provided
Time	45–60 min; ensure that patient/family is aware of the time allotment. If necessary, follow-up in the following days/week	Approx. 30–45 min	Limited time (<15–20 min)
Reassurance	Emphasizing: “First and most importantly, I want to reassure you that you are quite healthy and there is no serious problem to be concerned about”	Mentioning: no serious health problem	Not mentioned
One spokesman on behalf of the DSD team	Possibly jointly with medical team psychologist or social worker if one is available with experience with DSD	One spokesman on behalf of the DSD team	DSD team not mentioned

**Table 2** (continued)

Key item	Good	Reasonable	Insufficient
Explanation	Provides extensive explanation regarding the following key elements: 1. Typical development of ovaries/gonads and atypical development in gonadal dysgenesis 2. Genes and chromosomes 3. Hormones and hormone replacement 4. Female reproductive anatomy 5. Fertility/infertility 6. Potential tumour risk	Most items mentioned but limited explanation	Some relevant items not or incompletely mentioned; explanation from viewpoint chromosomal error: patient “being a girl by default”
Therapeutic issues	Hormone replacement during the teenage years (oestrogen and later progesterone); these hormones can be provided in many ways (pills, patches, sprays, creams, etc.) and have to be continued into adulthood	Some but not all items mentioned but no or limited explanation	Relevant items not or incompletely mentioned
Long-term implications	Sexual relationships; infertility; options to have a partner, a family Advice to share the condition only with close relatives or friends Offering psychological expertise	Some but not all items mentioned but no or limited explanation	Questioning female gender identity; relevant items not or incompletely mentioned
Follow-up	Outpatient clinic appointment for initiation of oestrogen treatment; subsequent joint appointment with urologist/surgeon or gynaecologist to discuss gonadectomy	Some but not all items mentioned but no or limited explanation	Not mentioned
Empathy	<i>Questions:</i> provides time for patient and parents’ questions and concerns <i>Checks understanding:</i> checks whether patient and parents understand the main messages <i>Written information:</i> provides a written summary of the discussion; provides any reading materials published by support groups <i>Support group:</i> provides contact information for local or online support groups		

ing is at least as effective as traditional learning approaches, and superior to no instruction at all in improving health care professional behaviour [10].

#### *Aim: Assessment for Learning*

We showed that e-learning which incorporates feedback can play an important role in assessing and learning communication skills for information sharing of DSD. We aimed to evaluate the assessment during the learning process where direct feedback to the learner is provided by a tutor in the context of e-learning. This is termed formative assessment, or assessment *for* learning [15]. It should be noted that fellows are in training to develop communication skills, and feedback from assessors can be used to enrich communication skills. In addition, we explored whether we could formulate generally applicable qualitative guidelines for formative assessment using a rubric method [16]. It is important to note that these guidelines were developed to stimulate discussion between fellow and expert and thereby improve learning. The questions were certainly not intended to be used for

fail/pass decisions at the end of the learning process (summative assessment, or assessment *of* learning) [15].

#### *Need for Structured Assessment and Applicability*

In our study, fellows worldwide showed a broad range of communication skills. In the fellows’ replies to the open question to accurately and empathically inform the parents of the newborn and the 17-year-old girl about each condition and its long-term consequences, we noted that many relevant items were not mentioned. These included reassurance, follow-up, long-term implications, and the role of the DSD team. In 15% (case 1) and 17% (case 2), the overall assessment of the replies was considered poor/insufficient by the experts. We were disappointed that very few fellows (5 out of 44) provided reassurance about general health and quality of life to patients and their families in these conversations [17].

Specific DSD conditions require certain considerations. When communicating with parents of a newborn baby with CAH, it should be realized that they are overwhelmed facing the prospect of caring for their infant.

Their ability to absorb information is limited [17, 18]. We provided guidelines that are in line with recent suggestions from parents on how to improve the initial information provided after their child's diagnosis [17].

In addition, direct communication with an adolescent means that the doctor must be aware of developmental issues that may be present. In communicating with an adolescent with DSD, it is important to realize that there are many concerns. These include the possibility of emotional distress and feelings of isolation at the time of diagnosis, the prospect of infertility, and the difficulty of sharing this information with their peers and romantic partners [19]. We noticed that these concerns were not addressed adequately in many replies from the fellows.

We have no detailed information on the previous exposure of the fellows to patients with DSD. We recognize that even in a large teaching centre, the number of patients with DSD is small. Furthermore, these fellows had not received formal teaching in their fellowships on communication in DSD. Our study identified a need in this area. Thus, providing e-learning material consisting of structured guidelines and providing a stepwise approach to virtual patients may be a welcome adjunct in fellowship training programs. Virtual patients can readily provide learners with multiple and varied case examples, while offering the opportunity to receive feedback, not only on the accuracy of the learner's diagnosis and treatment plan, and the information-gathering and decision-making path, but also on the quality of information sharing and communication with patients and families [20].

As a limitation of the study, we acknowledge that English was not the native language of many participating fellows, which may have influenced their understanding of the questions and formulation of their replies. It was not possible to make an analysis of the impact of language on the assessment, as no information on their fluency of English was available. Regional or national application of the e-learning portal may best be used with direct interaction between fellow (student) and expert (tutor).

#### *Use of Guidelines by Assessors*

We noted considerable diversity in the application of the developed guidelines by the participating senior endocrinologists. Differences between assessors is a well-known phenomenon: first, panels of experts may show differences in their personal performances [21]; second, differences between experts frequently exist in scoring and weighing assessments [22]; and third, differences in scoring may also be due to cultural and geographical differences. However, in our study, no correlation between

geographic origin and rating could be established. Obviously, non-verbal communication that may have nuanced the interpretation of the text passages was lacking. The voluntary time commitment asked of the assessors may have also contributed to the varied results. Experts were provided with model answers to the open questions to help reduce variability in their responses. However, they were not formally trained in the use of the guidelines prior to the study, which may be helpful to do in future studies to see to what extent consensus can be reached.

One conclusion is that the participating assessors in this study may differ in their opinions on what the best words to use are during this nature of consultation. Another possibility is that assessors themselves may differ in their communication skills. The selected assessors were not chosen as those specialized in communication skills, but were senior paediatric endocrinologists selected from amongst the most experienced in contemporary DSD practice in specialist centres. In practice, the paediatric endocrinologist often fulfils the role of spokesman in a DSD team, sometimes in the presence of a psychologist. Moreover, the endocrinologist is also responsible for offering face-to-face training of fellows in hospital practice. We would like to express our hope that senior paediatricians might become aware of these differences and work together to develop a (gold) standard for optimal communication in DSD. For future use of this learning method, we would like to make a plea to train the participating assessors, for example, by virtual group discussions on to how to best respond to the scenarios given. This would both enhance the skills of the "experts" and may improve the interrater scoring. Furthermore, this learning method may itself prove helpful for educating established physicians, and not just trainees, in the future.

#### *Creation and Ongoing Evolution of Guidelines for Assessment*

We created guidelines with input from international fellows and experts in paediatric endocrinology that can be applied for e-learning and assessment, and complement clinical experience, to improve communication about DSD. In order to prepare guidelines to assess communication skills of the fellows by the experts in the study, a rubric was developed as a structured approach for the development of scoring guidelines [23] (online suppl. Table 1). As the evaluation of the 5-level and 3-level assessment tool gave comparable results, we suggest that it is more practical to use the simplified 3-level rating scale: insufficient-reasonable-good (Table 3).

As we reported previously [9], it is of interest to note that the fellows in their first reply to the open questions did not mention cultural, religious or regional aspects. However, some acknowledged in their second reply to the expert that religious considerations are important, providing new insights for future use. Another important aspect not covered in these guidelines is the communication about strategies for sharing information (education and disclosure) with extended family and close friends. Finally, while the development of these guidelines has focused on the paediatric endocrinologist on the DSD team (an important starting point given the central role of the endocrinologist), we recognize that specialists from other disciplines on the team are (at least) as in need of assessment and learning of communication skills in DSD. It will be important to continue further refinement of these guidelines in close collaboration with all stakeholders, notably interdisciplinary health professionals and patient representatives, as evidence for best practice in DSD care continues to evolve.

## Conclusion

It is well established that interactivity, practice exercises, repetition, and feedback improve learning outcomes, and also that interactivity and online discussion improve satisfaction in relation to online learning (or e-learning) for health professionals [23].

In general, online learning has traditionally been used to foster skills in the knowledge domain (e.g., clinical reasoning) rather than in practical skills such as communicating with service users where face-to-face contact is required. However, online learning can be very useful when preparing for face-to-face experiences. Ideally, educators

will be best served by blending online learning and face-to-face instruction in individual or small group discussions [24–26]. In this context, e-learning can play an important role, not only for assessing medical knowledge, but also for assessing and learning communication skills [27] – of trainees, as well as physician educators. This method allows for practice in management and communication in DSD. While case vignettes and management advice in text books will quickly date, this method allows for evolving up-to-date practical advice and meaningful feedback from active practitioners. It is interesting to note that whereas communication training is routine for specialties like oncology, there is no requirement for practitioners and researchers in DSD to receive such support [17]. Based on recent guidelines [4–6], we provide a practical tool to assess how information is shared with patients with DSD and their families. This model may also be applicable to other chronic medical conditions.

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## Disclosure Statement

The authors declare that they have no conflicts of interest.

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