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# Evaluating the Term 'Disorders of Sex Development': A Multidisciplinary Debate

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# Evaluating the Term ‘Disorders of Sex Development’: A Multidisciplinary Debate

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## Abstract

In 2014, almost 10 years after the 2005 International Consensus Conference on Intersex in Chicago,<sup>1</sup> one of the conference co-organisers, under the auspices of a number of international paediatric endocrinology societies, launched the Global DSD Update to assess progress. A consortium of fourteen work groups conducted

online/email discussions to explore each of the fourteen key topics, one of which was use of the controversial medical umbrella term ‘Disorders of Sex Development (DSD)’. The initial key question for Work Group 1 (referred to hereafter as WG1) was to reconsider the nomenclature. Nineteen individuals from a variety of professional backgrounds, including medical practitioners, patient advocates, academics and psychologists, accepted invitations to contribute. This article is based on a transcript of the 6-month debate, collated using thematic analysis methods. Seven key themes were identified: a) Disorder of Sex Development – What does this mean? b) How useful is the word ‘Disorder’? c) How useful is the word ‘Sex’? d) Benevolent non-disclosure of terminology e) How useful is an umbrella term? f) The issue of evidence and g) Considerations for future nomenclature. This article also highlights the challenges in debating issues that straddle the medico-social interface, such as terminology, and between participants coming from different professional disciplines and epistemological standpoints. While recognising that such discussions can be useful and enlightening for all parties, this article recommends that a shared frame of reference be agreed by all stakeholders from the outset in order to provide a more fruitful basis for discussion.

**Key words:** Nomenclature, terminology, DSD, disorder, intersex, CARD

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## Introduction

The arrival of intersex support and advocacy groups from the late 1980s, e.g. Androgen Insensitivity Syndrome Support Group UK (AISSG UK) 1988 and Intersex Society of North America (ISNA) 1993, aided by the emerging use of the internet, prompted discussion within the affected community about the nomenclature used in this branch of medicine at that time; principally the terms based on ‘hermaphrodite’ in use since 1876,<sup>2</sup>

but also the term ‘intersex’ in use since 1917.<sup>3</sup> There was generalised criticism of the stigmatizing connotations of the former term.<sup>4</sup> Although some parents were not in favour of the term, ‘intersex’ was accepted by numerous affected adults as an ‘out and proud’ identity.

In 2005 Dreger, Chase, Sousa, Gruppuso, and Frader advocated replacing the hermaphrodite-based medical taxonomy with a similar umbrella term ‘disorders of sexual differentiation’, without recommending likewise for ‘intersex.’<sup>5</sup> During this time paediatric clinicians were responding to challenges from patient groups to provide a more informed and integrated system of care for affected infants and their parents. To this end, in 2005, two paediatric endocrine societies, the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology decided to conduct a clinical review: the Chicago consensus conference which comprised fifty invited delegates.

The new DSD-based nomenclature was adopted at the conference following some contribution from ISNA but without consultation with other support/advocacy groups. Since then there has been much debate about ‘DSD’ in support, advocacy, and academic circles.<sup>6,7</sup> Concerns identified include a) unease about the way in which it was introduced without a wider patient group consultation, especially outside the USA<sup>8,9</sup>, b) its implication of a pathological or disordered sexual identity<sup>10-12</sup>, and c) the way in which ‘intersex’ (a term that many affected adults were happy with) had also been replaced in a desire to assuage parents’ anxieties.<sup>13,14</sup> However, the societal side of the medical-societal interface has had little success in engaging clinical protagonists in discussion because of a general acceptance of the terminology within medicine.<sup>15,16</sup> One of the declared aims of the Global DSD Update was to redress some of these concerns.

WG1’s Key Question (a “reconsideration of the nomenclature and the conditions to be included”) was to be conducted by “presenting the pros and cons of current (DSD) nomenclature, together with comments about change”, and “with any recommendations or suggestions.”<sup>17</sup> Each working group was asked to record their conclusions, including any recommendations or consensus they reached, in the form of a short summary, so that all 14 could be consolidated into a single document.<sup>18</sup>

Following several months of discussion the group began exploring alternatives to the DSD terminology and was moving towards the term ‘Congenital Atypical Reproductive Development’ (CARD) or ‘Conditions Affecting

Reproductive Development’ (CARD), albeit without consensus. However, towards the end of the process WG1 was advised that it was not required to propose new terminology, and that its summary text could only present strengths and weaknesses of the existing DSD nomenclature, with no recommendations for change.

Consequently, there was concern amongst some participants that much of the significant parts of the debate would go undocumented. While the debate was complex and at times difficult, most of the contributors agreed that it was a very worthwhile endeavour that increased appreciation and understanding of the issues relating to the DSD nomenclature from a variety of perspectives. This article provides an account of the WG1 discussion in order to highlight the complexity of the debate, the concerns raised and attempts at finding a resolution.

### **Collation of WG1 Discussion Data**

The aim of this article is not to forward a definitive position with regard to the ‘DSD’ nomenclature but rather to provide an account of the discussion undertaken by WG1, highlighting the different issues that emerged and the group’s efforts to find solutions. However, as the discussion was long and complex, some method for accurately condensing the information was necessary and a social science method used in thematic analysis was identified as the most appropriate.<sup>19</sup> Thematic analysis does not attempt to produce ‘facts’ in the scientific sense of the word but “is a method for identifying, analysing, and reporting patterns (themes) within data.”<sup>20</sup> In this instance the raw data was the group’s email discussion from September 2014 to April 2015 which was organised into a linear transcript (80,000 words approx.). All personal information or information extraneous to the nomenclature discussion was discarded. All comments, points, and counterpoints made in relation to nomenclature (330 in total) were then organised in accordance with emergent themes and are presented in the sections that follow. The purpose of using this method is to provide a thematically organised account rather than to conduct a thematic analysis of the WG1 discussion. Though the article is thematically organised, the discussion itself was not. This made it difficult to neatly separate themes. Some themes do overlap in places, which is a reflection of the actual discussion.

Although the contributors may represent distinct and diverse professional groups (medical practitioners, patient advocates, psychologists, and

academics), the reader should not assume that the positions presented correspond to particular professional affiliations. There was considerable diversity of opinion between and within professional groups and individuals. Thus none of the perspectives presented in this document can be attributed solely to any particular professional group or individual. It should be noted that the concerns raised in relation to the DSD nomenclature reflect the language of the WG1 discussion: English. The appropriateness of the term cross-culturally and the meaning of the term when translated into other languages, while important, were not subjects of the WG1 discussion. All information contained in the themes below, including the corresponding references, is derived solely from the WG1 email transcript. The recommendations at the end of this article are compiled by the authors and are suggestions for facilitating future collaborations of this kind. It is hoped that the reader will view the following thematised account and recommendations as the product of a discussion between interested individuals who worked together in an attempt to address the problem of how to refer to atypical sex.

### **Discussion Themes**

This section explores the themes that emerged from the WG1 discussions: a) Disorder of Sex Development – What does this mean? b) How useful is the word ‘disorder’? c) How useful is the word ‘sex’? d) Benevolent non-disclosure of terminology e) How useful is an umbrella term? f) The issue of evidence, and g) Considerations for future nomenclature.

#### **Disorder of Sex Development – What does this mean?**

One of the main WG1 discussions regarding the ‘disorder of sex development’ nomenclature (henceforth DSD) related to the juxtaposition of the words ‘disorder’ and ‘sex’ and what it might be understood to mean. Contributors opposed to the term provided evidence from surveys<sup>21,22</sup> and anecdotes which indicated a lack of support for the term ‘DSD’ on the grounds that it was perceived as pejorative and stigmatising by patients/parents. While the word ‘disorder’ was deemed generally acceptable within a medical context when referring to a specific feature of the body affecting health, e.g. ‘adrenal steroid disorders’ or ‘endocrine disorders’, when combined with the word ‘sex’ this was recognised by some contributors as producing a multiplicity of potentially pejorative and stigmatising meanings.

Used within a biomedical context ‘DSD’ was recognised by some as a useful syndromic description to highlight the possibility of a range of underlying medical conditions that may indicate the need for further medical investigation. However, from a more general social perspective it was suggested by some contributors that the term ‘DSD’ can seem to refer to an individual possessing a pathological identity or who engages in deviant sexual behaviour.

However, it was noted by some contributors that the parents encountered at paediatric DSD clinics seemed generally untroubled by the ‘DSD’ nomenclature, and that concerns relating to the nomenclature may reflect the views of a small minority. In response it was pointed out that while patients/parents may be aware of the specific diagnostic term applied to their condition, e.g. ‘congenital adrenal hyperplasia (CAH)’ or ‘complete androgen insensitivity syndrome (CAIS)’, they may not be aware that the umbrella term ‘DSD’ also applies. It was further suggested that parents also tend to be in an anxious state when they attend DSD clinics, where their focus is on their child’s health. Thus the relevance of the DSD terminology to their child, initially at least, may not be apparent.

In contrast, a concern highlighted by several contributors was that parents/patients have expressed reluctance, or refused to participate in research where project titles contained the term ‘DSD.’<sup>23</sup> This was recognised as a serious problem since, as a field of knowledge, evidence-based treatment of these conditions has been repeatedly identified as lacking due to an absence of long-term outcomes research. Thus parent/patient reluctance to participate in research was recognised as having serious consequences for future treatment practice.

#### **How useful is the word ‘Disorder’?**

The term ‘disorder’ was seen as pathologizing by some in WG1. The concern was expressed that the inclusion of the term ‘disorder’ generated the assumption that anyone with a ‘DSD’ necessarily required treatment, which may not always be the case. It was also suggested that expectant parents are more likely to opt for termination when informed of a prenatal diagnosis involving the word ‘disorder.’ There was a concern that when combined with the term ‘sex,’ ‘disorder’ could be interpreted as referring to biological problems relating to sex assignment, i.e. that ‘DSD’ necessarily referred to a situation where a person’s assignment as male or female was unclear or problematic. This was recognised as a potential source of distress for

patients/parents and also as misleading or inaccurate since for most individuals currently included under the term 'DSD', sex assignment is straightforward.

However it was argued that while certain individuals may not have immediate health issues, the various conditions included under the umbrella term 'DSD' represented congenital disorders, or several different congenital disorders, relating to sex chromosomes, gonads or genitalia. Further it was suggested that medical terms such as 'disorder' are necessary to ensure that treatment consistently reflects best medical practice across all fields. It was also noted that there are parents/patients who favour the medicalising connotations of the term 'DSD' because it describes the patient as a girl/woman or boy/man with an illness rather than as deviating from the two sex/gender system, which is implied by terms like 'intersex.' The term 'DSD' had been ratified in Chicago with the aim of re-conceptualising DSDs as describing recognisable medical conditions rather than defining individuals' identities.<sup>24</sup>

A further point justifying the use of the 'DSD' nomenclature relates to patient/parent psychological adaptation. It was suggested that 'DSD' was an accurate term reflecting the biomedical reality of the patient's condition, thereby helping them to come to terms with, and adapt to their circumstances. It was therefore felt that changing the nomenclature to a term that did not reflect the biomedical reality of the conditions, i.e. did not refer to the atypicality of the patient's sex, may inhibit the patients'/parents' ability to recognise and address the full consequences of the situation and adapt appropriately. However, in response to this it was suggested that 'DSD' is not a diagnosis and does not provide specific or significant diagnostic information, therefore the term 'DSD' may do little to facilitate adaptation. It was noted that several significant diagnostic terms, for example 'CAH' or 'CAIS', provided the indicative information for adaptation without using the potentially stigmatising word, or combination of words, 'disorder' or 'sex'.

### **How useful is the word 'sex'?**

When contesting the use of the word 'sex', as mentioned earlier, much of the concern centred on the juxtaposition of the words 'disorder' and 'sex', the inclusion of which in 'DSD' was thought unnecessarily to raise uncertainty regarding the patient's sex/gender identity. However, there were concerns raised by some contributors relating specifically to how the word 'sex' carries different

meanings in different contexts and how interpretations might affect patient's/parent's perceptions of themselves/their child.

While medicine might use the term 'sex' to refer specifically to the developmental processes involved in sex determination and differentiation, within a social context it can carry a more 'whole person' meaning. And while medicine may recognise a distinction between sex (the body) and gender (the identity), within society this distinction is often blurred to the extent that the terms 'sex' and 'gender' are almost interchangeable. It was suggested by some contributors that sex is usually perceived as the physical core of gender and the ground on which gender authenticity is assumed to exist, thus any title which brought into question a patient's sex was perceived as calling into question the patient's gender. The term 'sex' can also refer to an individual's socio-legal status as male or female, their sex role within society, their gender identity and sexual orientation, and/or their sexual behaviour and preferences. A concern highlighted by several contributors was that patients/parents were already sensitive and uncertain about gender authenticity and that any compounding of this uncertainty was psychologically distressing. Thus it was proposed by some contributors that any future umbrella term not use the word 'sex' for this reason.

### **Benevolent non-disclosure of terminology**

Some contributors having experience of dealing with parents/patients agreed that the term 'DSD' may be interpreted as pejorative or stigmatising but suggested that it is not necessary to use the term when discussing diagnostic information with parents/patients. While the reasoning behind this was recognised as benevolently motivated, other contributors pointed out that patient/parents now have unprecedented access to information from medical, advocacy and social media websites, and that they are likely to become aware that the term 'DSD' applies to their situation. The concerns here were:

- that patients/parents may become aware of the terminology in an unsupported environment, i.e. non-medical context where they are not in a position to ask questions about what 'DSD' might mean
- that when parents/patients become aware that the nomenclature associated with their situation had been withheld, this could compound feelings of stigma because it implies that the condition was so shameful it could not be named
- that this may in turn impact the relationship of

trust between the parents/patients and the clinician where the clinician's behaviour may be seen as dishonest or controlling.

Thus it was suggested that in the interest of full and honest disclosure, clinicians must feel that the terminology employed is appropriate for use in speaking with patients/parents. If clinicians are motivated by fears of stigma or offence to avoid such use, then the nomenclature is not optimal. With increased public access to medical literature, medicine must recognise the increasing social visibility of its terms and evaluate them within this broader social context, taking into consideration possible alternative meanings and their impact.

### **How useful is an umbrella term?**

Another theme that emerged in the course of the WG1 discussion was whether an umbrella term was necessary or advantageous, and if so, what conditions ought to be included under its remit. It was noted that since the publication of the Chicago consensus statement there had been considerable, as yet unresolved, debate among various endocrine societies and individuals regarding what conditions ought to be included under the term. It was suggested in WG1 that an umbrella term implies that all patients thus categorised share common diagnostic characteristics, making it likely that they will benefit from a common model of care. However, since no single diagnostic characteristic unites such individuals, the concern was that clinicians may assume a particular set of medical, surgical or psychosocial needs applies to an individual with a DSD, based on the experience of treating a different DSD group with entirely different needs, thereby resulting in the individual's needs not being correctly identified.

WG1 engaged in considerable discussion but arrived at no definitive agreement on what diagnostic features ought to be employed to unify a common umbrella term. Depending on the perceived source of concern, whether sexual, reproductive, genetic, gonadal, genital, hormonal, or morphological, the umbrella shifted backwards and forwards to include or exclude different groups of patients. It was suggested by some contributors that the primary unifying principle grounding the term 'DSD' appeared to be *exclusion* from what was regarded as normal sex determination and differentiation rather than *inclusion* based on any common set of characteristics. Issues relating to fertility, sex assignment, hormone therapy and surgery were identified as relating to patient groupings under the DSD umbrella but none of

these could be ascribed to all groupings. Recognising the breadth and diversity of the DSD umbrella term and its limited utility as a diagnostic descriptor, some contributors began to question whether an umbrella term (whether 'DSD' or any other term) really carried medical merit, but if so, what grounds should be used to unify patients under the term. Despite these concerns, several reasons in favour of having an overall umbrella term were recognised; these included:

- acknowledging that as it can take time to identify a specific diagnosis, it can be useful to have a syndromic term by which the patient's condition can be initially referred.
- the syndromic term can help direct medical practitioners' attention and can help quickly identify likely approaches to care or initially target specific expertise or explorations.
- an umbrella term can help focus teaching practices and research, and make more efficient use of available funding.
- it may provide patients/parents with a reassuring label indicating that the condition is familiar rather than unknown to medical practitioners.
- in the absence of a specific diagnosis it provides clinicians with appropriate language, thereby avoiding accidental use of inappropriate or stigmatising language which may inadvertently leave a lasting negative impression on patients/parents.
- since multidisciplinary clinics are costly to run, it would be inefficient for any healthcare system to run clinics addressing the particular issues pertaining to all the sub-categories currently coming under the DSD umbrella. Thus while recognising that there are differences between various sub-categories it may be more prudent to focus on the similarities in order to pool resources and expertise under a single umbrella term.

### **The issue of evidence**

A major methodological theme to emerge during the discussion was the issue of evidence. At the outset the group was asked to comment on the strengths and weaknesses relating to the nomenclature and to support their comments with evidence. However, it was eventually recognised that evidence, in the scientific sense of randomised controlled trials was not applicable. Contributors who had sought the opinions of patients/parents belonging to advocacy or support groups described how the majority of the patients/parents they encountered did not like the term 'DSD' and were

unwilling to associate with the term. These findings were presented to the WG1 as anecdotal evidence showing a lack of support for the 'DSD' nomenclature. Some contributors argued that this was not acceptable as valid evidence that could be used to justify changing the nomenclature, because it lacked scientific rigour and was felt to be prone to bias by reflecting the views of a self-selecting group. However, it was pointed out that the term 'DSD' was itself introduced without the benefit of scientific evidence but on the strength of anecdotal evidence.

By way of evidence suggesting satisfaction with the 'DSD' nomenclature it was argued that increasing numbers of biomedical articles employed the term 'DSD.' However, other contributors felt that this also did not constitute evidence because use of particular terminology may reflect a lack of acceptable or meaningful alternatives rather than constituting evidence of satisfaction with the existing nomenclature. As the discussion progressed it became clear that there was little agreement on what constituted proper evidence and that if in the future a consensus was to be reached all parties would have to first agree on what might constitute acceptable evidence and therefore what evidence might justify maintaining or changing the nomenclature.

It was suggested that in the decade since the Chicago consensus statement the absence of published scientific research showing a lack of support for the 'DSD' nomenclature was indicative that it was unlikely that there was a groundswell of opposition for the term. However, it was pointed out that while clinicians are able to avail of funding to engage in such research, advocacy organisations are run by unpaid volunteers operating within limited budgets and who do not have the academic experience or financial capacity to produce scientific research reflecting the preferences of their community. Thus it was argued that a lack of published material could not be interpreted as indicating support or otherwise for the 'DSD' nomenclature. It was pointed out that the evidence produced by advocacy organisations is derived through direct communication with service users and is necessarily anecdotal. Some of the contributors were skeptical that anecdotal evidence could be accepted as proof of patient/parent preferences and hence included in the discussion; but others felt that such anecdotal accounts indicating significant dissatisfaction with the 'DSD' nomenclature certainly suggested, at the very least,

an immediate need for further scientific investigation.

Another obstacle identified in the production of evidence-based research on patient/parent preferences related to the lack of access to research participants. For most patients/parents the first port of call is a hospital or medical centre where information on each patient is gathered. This means that clinicians working within these institutions have exclusive access to data and/or potential research participants. However, confidentiality considerations and privacy concerns mean that anyone operating outside the realm of medicine, such as advocacy organisations and academic researchers, are at a distinct disadvantage in attempting to conduct research.

Further it was suggested that since medical practitioners are likely to investigate issues of particular concern to medical practice, medicine's greater access to research data may be producing a biomedical bias in terms of the kind of knowledge produced. Thus different perspectives or concerns pertaining to different areas of interest, such as psychosocial outcomes may be underrepresented in the literature. Within this context 'DSD' may be contributing to this bias by being situated firmly within biomedical discourse.

A final concern relating to evidence articulated by some was the priority given to parental concerns over the concerns of affected adults within the literature. It was recognised that much of the research and resultant literature regarding DSDs was emerging within paediatric medicine. While the deeper understanding and improved treatment practices were obviously welcomed, it was also noted that within the fields of paediatric medicine clinicians primarily engaged with parents, thus, it was suggested, their concerns unsurprisingly reflected the interests of those parents.

Concern was expressed that this led to an unintentional but significant bias in favour of parental concerns within the medical literature, while the interests of affected adults remained comparatively invisible.

### **Alternative terminologies**

The table on the next page offers alternative terminologies considered by the WG1.

### **Considerations for future nomenclature**

None of the advocacy agencies engaged in the WG1 discussions endorsed the 'DSD' nomenclature, with most referring to the combination of words 'disorder' and 'sex' as the primary reason. Such



## Alternative Terminologies

Terms suggested	by whom
Prior to Global DSD Update	
Variations in Reproductive Development (VRD)	[25]
Intersex	Various
Diverse Sex Development (dsd)	[26]
Differences of Sex Development	Various
Variations of Sex Development (VSD)	[27]
During the Global DSD Update	
<b>Terms using 'Reproductive'</b>	
Atypical <sup>a</sup> Development of the Reproductive System (ADRS/ADRT) <sup>b</sup>	PE/SAG
Atypical Reproductive Tract <sup>c</sup> Syndrome/s (ARTS)	SAG/AR
Atypical Genital Reproductive Development (AGRD)	PU
Conditions Affecting (or Involving) Reproductive Development (CARD, or CIRd)	PE/SAG
Conditions Affecting the Reproductive Tract (CART)	SAG
Conditions Affecting Development of the Reproductive System (CADRS)	PE/SAG
Conditions Related to Reproductive Development (CRRD)	PE/SAG
<b>Conditions Affecting Reproductive Development (CARD)</b>	PE/SAG
<b>Congenital Atypical Reproductive Development (CARD)</b>	PE/SAG
Developmental Variation of the Reproductive System (DVRS)	AR
Developmental Conditions of the Reproductive System (DCRS)	PE/SAG
Differences of Reproductive Development (DRD)	AR/SAG
Disorders of Reproductive System Development (DRSD)	PE
Disruptions of Reproductive Development (DRD)	PE/SAG
Exceptions in Reproductive Development (ERD)	PE/SAG
Genital Reproductive Atypical Development (GRAD)	PU
<b>Terms using 'sex/sexual'</b>	
Atypical CAGS (CAGS = Chromosomal, Anatomic, Gonadal Sex)	PE/SAG
Conditions Affecting Sex Development (CASD)	AR
Diverse Sex Development Also Known as Intersex (DSDI) or	SAG
Intersex Also Known as Diverse Sex Development (IDSd)	SAG
Variations in Sexual Expression (VSE)	SAG
<b>Terms Using 'Genital'</b>	
Congenital Anomalies of Genital Development (CAGD)	PE
Congenital Adrenal and Genetic/Gonadal/Genital Endocrine Syndromes (CAGES)	E
<b>Other Terms</b>	
Situation of Atypical Gender Assignment	AR

Notes: <sup>a</sup>: or Non-Typical ; <sup>b</sup>: Tract was offered as an alternative to System; <sup>c</sup>: System was offered as an alternative to Tract. See page 8 for a list of who offered these suggestions

groups were actively trying to dissociate themselves from the term or were employing different less pejorative terms in their version of the 'DSD' acronym where 'disorder' was replaced with the word 'difference' or 'diverse.' This naturally led to detailed discussions within the work group regarding the best term to use to describe the collection of conditions currently coming under the DSD umbrella. The discussion relating to alternative nomenclature was long and complex. What is presented here is a simplified and condensed version and therefore cannot convey the depth, nuance and full complexity of the discussion.

While the words 'variant' and 'variations' were suggested as a replacement for the word 'disorder'

there were those who deemed this inappropriate because it implied 'normality' and might give the impression that medical intervention was never necessary. The word 'reproductive' was suggested as a replacement for 'sex' because it incorporated chromosomes, gonads, hormones, internal/external genitalia and morphology without referencing sex or gender. There was a concern that such an emphasis on 'reproduction' might mean that anyone experiencing fertility issues might now be included under the umbrella. Given that this would make the reference group massively broad, it was then suggested that use of the words 'congenital' or 'development' within the term would refer to conditions arising prenatally rather than conditions

that emerged post-pubertally, reducing the coverage to that which is currently referred to under the 'DSD' nomenclature.

The table lists the main alternative terms suggested outside of, and inside the WG1 discussions by participants from the following professional backgrounds:

- AR=academic researcher,
- E=endocrinologist,
- PE=paediatric endocrinologist
- PU=paediatric urologist,
- SAG=support/advocacy group.

Towards the end of the discussion those still active in the group moved towards agreement in relation to the term 'Congenital Atypical Reproductive Development' or 'Conditions Affecting Reproductive Development,' both terms employing the acronym CARD (highlighted in bold italics in the table). While the former was seen as medically more accurate, the latter was seen as less clinical and therefore potentially less alarming for parents/patients. While there was considerable support for both terms among the remaining members of WG1, CARD cannot be regarded as a consensus term of WG1 as it reflects agreement among a sub-set of members rather than the entire group. (See table)

During the discussion on identifying an alternative umbrella term it was agreed that representatives of additional advocacy organisations (e.g. for Turner and Klinefelter's Syndromes) be brought into the group, to broaden discussion of what conditions might sit comfortably under a new term. Towards the end of the discussion the group learnt that recommending a new term was not within its remit as far as the summary document was concerned and was asked to refocus its efforts on presenting an evaluation of the strengths and weaknesses of the 'DSD' nomenclature. However, before the discussion on nomenclature came to a close a number of factors were identified as important for future explorations of possible alternative terms:

- The term should highlight the possibility of relevant health implications and should therefore be medically meaningful.
- In selecting a term there should be clarity as to why an umbrella term is necessary, what criteria will be used as unifying criteria and what purpose this unification serves.
- The term should avoid any words that might be interpreted as pejorative or disrespectful.
- The term should not employ the word 'disorder' because it implies that something necessarily

- needs medical fixing, which is not always the case
- The term should not employ the word 'sex' as this could increase uncertainty/anxiety about gender in an already sensitive group.
- The term needs to accurately reflect the biomedical issues relative to the conditions.
- The term should be easy to articulate and be as simple as possible to allow for easy communication between patient/parents and clinicians; preferably it should reduce to a neat acronym.
- The term should emerge from, or at least be acceptable to those to whom it will be applied (this identifies a need for further extensive research into patient/parent preferences).

## Recommendations

During the discussion WG1 identified several factors that may facilitate future collaborations of this kind. These are presented below as a list of recommendations.

1. In gathering evidence or considering changes relating to, or affecting a diverse group, representatives from all stakeholders should be included and consensus agreed. Stakeholder groups should include affected children, affected adults, patient advocates, parents, paediatric experts, experts in adult medicine, psychologists, social-workers, and where possible, ethicists.
2. If collaboration is sought among medical and non-medical experts regarding the evaluation of a particular medical practice then it is important that an agreed framework be established in which certain rules of engagement are agreed from the outset regarding for example: identifying the problem to be resolved, the aims and objectives of the collaboration, an agreed methodology, what constitutes permissible evidence/justification, agreed use of language/behaviour, who has authority/power of veto, etc. Without this, the benefit of insights derived from collaboration with diverse expert perspectives may be lost due to an absence of common grounds for communication.
3. While the medical societies sponsoring explorations such as this have recognised the benefits of collaborating with diverse groups of expertise, there is a considerable discrepancy in research funding available to those diverse groups, thus some collaborators only have a limited capacity to produce evidence acceptable to biomedicine. Where it is deemed beneficial to acquire outcome evidence from alternative

perspectives it would be prudent to explore opportunities for sharing resources through collaborative research projects involving these diverse groups. In this way the evidence produced may have considerably broader application and utility across a range of disciplines, fuelling further collaborations.

## Conclusion

In seeking a multi-perspective assessment of the ‘DSD’ nomenclature WG1 welcomed contributors from diverse areas of expertise, including medical practitioners, patient advocates, psychologists and academics, who collaborated to address the emergent issues. The original aim of the group was to provide a strengths/weaknesses analysis of ‘DSD’ and was understood to allow a reconsideration of nomenclature, resulting in an in-depth discussion of concerns and an exploration of alternative terminology. This resulted in a rich, nuanced and complex appreciation of the issues, one which doesn’t fit neatly into a simple pro/con assessment of the ‘DSD’ nomenclature. It is hoped that this article has not only highlighted the complexity of these issues and concerns but has also illustrated the contribution a multi-perspective collaboration of this kind can make to future explorations.

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This article provides a thematised account of the discussion involving nineteen contributors to Work Group 1 within the Global DSD Update. Six of these contributors are listed as authors above. Nine of the remaining thirteen contributors agreed to be listed as affiliates to this article through choosing one of two options: either to be unconditionally affiliated (see Group 1) or to be conditionally affiliated by having it acknowledged that there are aspects of or positions outlined in the article with which the contributor does not necessarily conform (see Group 2).

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