Feedback form

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Please provide a brief description of the organisation (if applicable)	
Address/email	
Interest in this topic (eg, user of fertility services, health professional, researcher, member of public)	Research (PhD student looking at lesbians' decision making around donor sperm, and their experiences of fertility and maternity services).

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Question 1: Rescinding the biological link policy

Refer to section 3.

ACART is proposing that:

- the guidelines should no longer require intending parents to have a genetic or gestational link to a resulting child
- instead the guidelines should require ECART to be satisfied that where intending parents will have neither a genetic nor a gestational link to a resulting child, the lack of such links is justified.

(a) Do you agree? Yes [X] No [ ]

(b) Do you believe there are cultural implications associated with the proposed removal of the biological link policy?

Yes [X] No [ ]

If so, please describe these implications.

1) The current guidelines support cultural understandings that families are primarily linked and defined by genetics. The Status of Children Act 1969, as explained in the Consultation Document (p15), states the woman who gives birth to a child is regarded as the child's mother. While traditionally the woman who gives birth to a child has been genetically related to the child, this is no longer automatically so in Aotearoa New Zealand today, due to assisted reproductive technology. Assisted reproductive technology is changing how a family can be and challenging many cultural understandings of family. It therefore seems imperative that such guidelines are supporting the complex reality of families today, some of which are not grounded in biological links.
2) Lesbians and women having children with other women may be both medically infertile and socially infertile (they need sperm). In this case these women have no options in Aotearoa New Zealand and travel overseas where they can get fertility treatment. One of the mandates of this Consultation states:
"ACART has previously advised the Minister of Health on the issue of importing and exporting gametes and embryos. Broadening the scope of available assisted reproduction procedures will encourage New Zealanders to access such procedures in this country, with better safeguards and outcomes for resulting children. Treatment in New Zealand also avoids the pitfalls of trans-border reproduction such as difficulty in bringing offspring back to New Zealand." (p.iii).
Removing this biological link policy will certainly assist this group of women, as well as single women (of all sexualities) who are socially and medically infertile.

Please give reasons for your views.

See above.

Question 2: Access to information held on birth certificates

Refer to section 3.

ACART is interested in hearing views about potential strategies to strengthen a donor offspring's access to information about their origins, which is held on their birth certificate.

Do you have suggestions? Yes [X] No [ ]

Please give reasons for your views.

I agree further information could be held on birth certificates but don't agree with the proposed suggestions.

1) I don't agree with the Law Commission proposal *"In addition, Births, Deaths and Marriages should consider allowing parents to choose to have an annotation stating that the certificate's owner was born by 'donor'."*

Heterosexual couples have an extra challenge in how to let their children know they were conceived from donor gametes, and indeed whether they even tell their children.

a) if parents aren't going to tell their children they were conceived from donor gametes it is doubtful they will opt in to having an annotation saying 'donor' on their child's birth certificate. So, this option will not help strength the child's access to information about their origins.

b) if parents do opt in and put 'donor' on their child's birth certificate this is potentially problematic. Being a donor child may have stigma attached to it. Also, a child may know they are a donor child but may not wish to share that with people, or may wish to share that information with selected people. This is in a section titled *"Children have interests to be protected"*, and one of those interests must surely be a child's right to share their own origins? A birth certificate is an official document and used for many things and seen by many people. If there is an annotation on the birth certificate, then that removes the child's choice of who they share that information with.

2) The Law Commission also proposed: *"They recommended all birth certificates be amended to include a statement indicating that the Births, Deaths and Marriages register contains other information that may be accessed by the certificate's owner."*

An option may be to put this statement only on the birth certificates of those conceived with donor gametes. That way there is a prompt, but it is much more discrete. This would only work if it was administrative, and not an opt-in decision.

For children born through surrogacy and therefore adopted, an annotation on their birth certificate could be part of the administration process of adoption.

3) Consideration should be given as to whether it would be a rule for everyone conceived from donor gametes or just for those births with mother/father birth certificates. With the other birth certificates (mother/other parent and mother only) parents cannot hide that there is a gamete donor. Lesbian parents, women who have children with other women, and gay men who have used surrogates, have their own ways of sharing the creation stories of their children and do not require their children to be singled out further in official documentation.

Question 3: Format of the proposed guidelines

Refer to section 4.1.

ACART is proposing to issue one set of guidelines to ECART that encompass family gamete donation, embryo donation, the use of donated eggs with donated sperm and clinic-assisted surrogacy.

Do you agree with the format of the proposed guidelines? Yes [X] No [ ]

Please give reasons for your views.

Common language is very important.

Also having one set of guidelines may then only require filling out one form, rather than up to three. It may also benefit ECART, as they may only need to consider one form rather than three, which may require less time.

Question 4: Justification to use a procedure

Refer to section 4.2.

ACART is proposing that ECART should be satisfied the proposed procedure is the best or only opportunity for intending parents to have a child and the intending parents are not using the procedures for social or financial convenience or gain.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

All procedures should be available for people affected by either medical infertility or social infertility.

Note: I question the validity of this stated impact of the proposal:

> **104 Provide for cases where donated sperm was not available**: The removal of the medical criteria for using a donated embryo would provide for any cases where a lesbian couple or a single woman could not access donated sperm through a clinic but was offered a donated embryo. Embryo donation for these women might, in some cases, reduce the incentive to use donated sperm outside a clinic setting.

This scenario is extremely and highly speculative in the case of lesbian couples, and I question whether it is a reputable consideration. As mentioned in the Consultation Document "most intending parents will prefer to have a genetic or gestational link to resulting children" (p.iii). Lesbian parents and women who chose to have children with other women are no different.

I doubt that a lesbian couple looking for donor sperm would choose to have a donated embryo rather than continue seeking sperm outside the clinic. This scenario also presumes that the original intenders of the embryo will re-donate to a lesbian couple. It also presumes the lesbian couple would go through the highly medicalised process of IVF rather than the considerable less medical process of an IUI. It also presumes the lesbian couple would have the money to pay for a considerable more expensive IVF process, rather than a cheaper IUI process, or the free option of sperm outside the clinic.

Question 5: Consent by gamete and embryo donors

Refer to section 4.3.

ACART is proposing that, where a procedure will involve the use of an embryo created from donated eggs and/or donated sperm, the gamete donor(s) must have given consent to the specific use of their gametes:

- at the time of donation; or
- when a procedure using such an embryo is contemplated.

In either case, the affected parties should receive counselling on the implications of using gametes before the gamete donor gives specific consent.

If consent is given, the gamete donor can vary or withdraw their consent only up until an embryo is created (in cases where consent is given before the embryo is created).

In addition, where a procedure will involve the use of a donated embryo, the person(s) for whom the embryo was created must give consent to the specific use of the donated embryo:

- at the time of donation; or
- when a procedure using such a donated embryo is contemplated.

Once an embryo is created, the decision to vary or withdraw consent up to the time the embryo is transferred to the womb should remain with the people for whom the embryos were created.

Do you agree? Yes [X] No [X]

Please give reasons for your views.

Yes I agree with the proposals that people should consent to their gametes being used, they should consent to how they can be used, and they can withdraw their consent until such time that their gametes are used.

This follows ACARTs own advice about informed consent. Given there is a change to how gametes may now be used, presumably this will be EXPLICIT consent with regard to gametes use for a donated embryo.

Yes and No: consent about use of embryo by those for whom the embryos were created.

I agree the people for whom the embryos were created should have consent for their own use. If they agree to re-donate extra embryos to other person(s) then the original person(s) have consent up until their agreement to donate re-donate the embryos. Once there is agreement to re-donate the embryos, consent then moves to the receivers of the re-donated embryos.

This is because embryo donation requires IVF. It is acknowledged this is a stressful time for those undertaking treatment, particularly for straight couples who come with a history of infertility. If consent still lies under the original person(s) until the re-donated embryo is in the womb of the woman who is receiving the re-donated embryo, the woman receiving the re-donated embryo is subjected to extra stress, wondering if consent will be revoked as she goes through the initial stages of IVF. The original person(s) will have decided their family is completed, before donating extra embryos, and their consent should end when the donated is agreed.

Question 6: Taking account of potential coercion

Refer to section 4.4.

ACART is proposing that ECART should take account of any factors in a relationship that might give rise to coercion or unduly influence a donor's or surrogate's consent to take part in a procedure.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

And as discussed in the Consultation Document this should include donors / surrogates who are financially dependent and those who are living in the same house.

Question 7: Limit to number of families with full genetic siblings

Refer to section 4.5.

ACART is proposing that full genetic siblings should continue to be limited to no more than two families.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Having a two-family limit helps reduce the number of re-donation cases. If the number of families a donor can donate to is five, it seems reasonable that full genetic offspring be reduced to under half of that.

Other considerations:

1). Language.

I strongly advocate for the removal of the word "sibling".

Language is very considered and deliberate in the Consultation Document, to ensure inclusion. The use of "siblings" is very jolting. It is:

a) definitionally wrong in the context of the document (as siblings have shared 'parents' and this discussion is about donors and intended parents. A donor is not ever regarded as a parent)

b) continuing the problematic assumption that a family is based on genetics, and therefore if children are genetically linked they must be related.

c) inconsistent with ACARTs proposal to remove the biological link policy.

Instead of *"Number of families with full genetic siblings"* it could be replaced with *"Number of families with full genetic offspring".* "Offspring" is a term used frequently in the Consultation Document.

2) Clarification of "families".

Can I please request explicit clarification of what ACART means by "two families" (and by extension, what is meant by "five families", i.e. donors may donate to "five families").

Clinics seem to have ethereal definitions of "five families" and how this works in their individual clinics. For lesbian couples and women having children with other women this has caused huge distress, conversations with the Human Rights Commission, an unknown donor being in charge of how many children they have, all at a time that is already fraught with emotion. Currently, what can happen is a lesbian couple reserve some sperm. Partner A has a child. They come back to the clinic for Partner B to have a child. They are then told that they are actually two families (which is insulting and wrong) and the sperm has already been allocated to four other families, and so Partner B may not use the sperm.

If it is five families, then a lesbian couple is one family and they can both choose to have a child with the donated sperm. If it is five women, then this needs to be written and made explicit so lesbians can make informed decisions about whether one or both of them may choose to have children.

The reasons for limiting full genetic offspring to two "families" are outlined:

121. The current provisions that limit full genetic siblings to a maximum of two families exist to manage the number and complexity of relationships between parties and to ensure the risk of consanguinity (blood relationships) is minimised. The proposed changes noted above mean that the issue should be considered for all applications where embryos are to be or have been created.

One issue raised in this reasoning is social relationships. So whether one or both lesbians have a baby is irrelevant, they are one family, and therefore the terminology can stay as "families". Explicitly stating that a lesbian couple and women having children with other women are regarded as one family would be beneficial to both clinics and their clientele.

The other issue raised in 121 above is consanguinity. So if one lesbian has a baby and then another her partner has a baby, this may have issues of consanguinity, according to 121. I would argue that they are being raised as one family and so any issues around consanguinity for one would also be an issue for the other child. However, if technically this approach was to be taken, then please change the language to "women". This will increase clarity, and reduce stress, angst and alienation of lesbian clients when they are told they are two families.

Question 8: Legal advice

Refer to section 4.6.

ACART is proposing that ECART must be satisfied that:

- where an application includes a surrogacy arrangement, each affected party has received independent legal advice
- where an application does not include a surrogacy arrangement, each affected party has considered seeking independent legal advice
- any legal reports show that all affected parties understand the legal implications of the procedure(s).

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Surrogacy requires adoption so legal advice should therefore be mandatory. Embryo donation is similar to gamete donation, where the intended parents are also the gestational mother (and her partner if applicable), so legal advice should not be mandatory.

Question 9: Regulation of all family gamete donations

Refer to section 5..

ACART is of the view that all family gamete donations through a fertility services provider should be regulated by guidelines and thus require ECART approval.

Do you agree? Yes [ ] No [X]

Please give reasons for your views.

No. Regulation should only be required by those who have medical infertility.

If there is a preference for clinics to be involved so that ethical and legal issues can be better managed (see #80 for example), then introducing this regulation may prohibit clients from using clinics. In cases of social infertility (i.e. lesbian families), there are already and obviously families being made outside of the clinics and therefore outside of ACART and ECART provisions. By introducing mandatory regulation to social infertility, and making clients pay for it, the risk is that clients will chose to remain outside the jurisdiction of ACART and ECART (this is recognised for surrogacies #179, under Question 13). Repercussions include children not having access to information because they are not registered on the HART donor list.

179 **Some surrogacies in New Zealand would continue to be excluded from ECART review**: An unknown number of surrogacies in New Zealand do not use a clinic. Such arrangements would continue to be outside clinic or ECART oversight.

Lesbians, and women having children with other women, may increasingly choose to inseminate outside the clinic if this regulation is included for reasons including increased cost and the potential increased wait (presuming ECARTs workload will increase). Brothers and sisters who are heterosexual probably don't consider what they would do if their siblings were medically infertile. Being asked to donate sperm is a different decision for them than for families with lesbians, for example, where there is long-term recognition that their sister and her partner will need sperm for a family.

Note: I question the validity of this stated Rational for the proposal:

136 Risks include confusion about relationships, potential coercion and inheritance of family genetic conditions. For example, a child born to a woman who has used her uncle's sperm to conceive might be uncertain who their 'real' father is.

Any child of a donor might be uncertain who their 'real' father is. Whether this is an uncle or not. This potential is a potential for <u>any</u> child, and not just those who use a related donor. It could be argued that it is easier for a child to distinguish roles when the donor is related because they can frame them as uncle and therefore part of the family, compared to an unknown donor where there is an important but not familial link, and so therefore the desire to claim a relationship may make this more confusing. Also if an uncle is donating, under current rules, the family would need to apply for ECART approval anyway, so this example is not pertinent to the proposed l changes. Also this exert is from 2012 and American. If this is the most relevant research that could be found it is a strong indication that more research needs to be done in an Aotearoa New Zealand context for decision making to be informed.

Note: I question the validity of this stated Rational for the proposal:

139. In addition, it is fair that all family gamete donation cases be treated the same. The current differentiation between types of family relationships does not appear to be logical and, as set out in Part 2(2) of the HART Order, is unduly complicated.

1) I do not understand how it is "unduly" complicated. You could argue that the whole HART Order is "unduly" complicated. Part 2(2) is not more nor less "unduly" complicated than any other part.
2) Lots of things can appear to be not logical. A logic behind the types of family relationships can be easily inferred: it is relationships that are the same generation (cousins are included, uncles and aunts are not), and thus also includes immediate family members (brothers and sisters).
3) It is not about 'fairness'. If life was "fair" infertility would not exist. Different situations require different approaches. Medical infertility is different to social infertility. One is a situation of despair, one is a situation of opportunity. The concept of 'fairness' is completely unsuitable for a document dealing with how people are choosing to create their families. None of the other proposals have used the word "fair" or considered fairness. "Is it fair that guidelines should no longer require a gestational or genetic link between intending parents and a resulting child?"

Question 10: Donation of embryos created from donated gametes

Refer to section 6.1.

ACART is proposing that the guidelines should enable ECART to approve the donation of embryos created from donated eggs and/or donated sperm, provided ECART takes account of the potential complexity of resulting relationships and the gamete donors have given specific consent to the procedure.

Do you agree? Yes [X] No [X]

Please give reasons for your views.

Yes: For those families who have used donated gametes, and have surplus embryos.

No: For clinics creating embryos from donate eggs and donated sperm.

Question 11: Embryo on-donation and re-donation

Refer to section 6.2.

ACART is proposing that surplus donated embryos:

- should not be able to be on-donated by the recipients
- but can be returned to the donors, in accordance with any agreement between the parties, for re-donation to another party, subject to a new approval by ECART.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

As mentioned in Question 10, I don't think clinics should create embryos with donor eggs and donor sperm.

However, if clinics do create embryos, there should be a right of re-donation, and this means that only one family at a time should receive the embryos, and they have rights over the embryos until their family is finished, and then a decision is made about re-donation (or not). The clinic should not give created embryos to two families at the same time (as is potentially possible under Question 7).

The right of re-donation should rest with the first / original embryo receiver. The first / original receiver should have the right in agreement to ask that re-donation NOT be possible. That is, if they have children and there are remaining embryos, they have the right (not the clinic) to ask that the embryos not be donated, but the embryos be disposed of in accord with section 10 of the HART Act. This should be explicit in the agreement.

Some people are desperate to have children and will agree to anything to get a donated embryo. They may not be thinking clearly about consequences for their imaginary and not yet achieved family.

This section is not clear if recipients can choose to NOT return surplus embryos, but dispose of embryos in accord with section 10 of the HART Act.

Question 12: Clarification of the status of embryo donation in the regulatory framework

Refer to section 6.3.

ACART is of the view that the regulatory framework should clarify that:

- all embryo donation cases are regulated by guidelines and thus require approval by ECART
- embryo donation does not include cases where an embryo created for a couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

Do you agree? Yes [ ] No [X]

Please give reasons for your views.

Embryo donation SHOULD include cases where an embryo created for one couple is used by one of the couple in a new relationship with the informed consent of the previous partner.

With embryo re-donation, consent of the original gamete donors is required, and this situation should not be any different. With new relationships, situations and decisions can change, and consent should be given for the new partner in the new relationship. Consent should be "recent", and defining this would be too complex. Including all re-donation situations as 'embryo donations' removes this complication. Consent should be required from both of the original couple to be re-donated. Otherwise this is a case of on-donating, where the original donor doesn't have a say. On-donation clearly contravenes 6.2.1 Rational for the proposal around On-donation and Re-donation (152 and 153).

Also, although 'consent' may have been given, ACART and ECART will not know whether this consent is coerced or not. One of the Principles of these proposed amended guidelines is "the health and well-being of women must be protected in the use of these procedures" (p.2). This protection should extend to limiting situations of coercion.

Question 13: Regulation of all clinic-assisted surrogacies by guidelines

Refer to section 8.

ACART proposes to recommend that all clinic-assisted surrogacy cases be regulated by guidelines and thus require ECART approval.

Do you agree? Yes [X] No [ ]

Please give reasons for your views.

Yes because it is surrogacy not adoption. A surrogate is not getting pregnant accidentally and deciding to adopt her child out. A surrogate is using her own egg with the intent of adopting out. It is a deliberate pregnancy with an agreed upon outcome before the pregnancy exists. This is surrogacy. Therefore, she and the intending parents should be afforded the same regulations as other surrogate arrangements.

172: Most clinic-assisted surrogacies in New Zealand are followed by adoption through the Family Court under the Adoption Act 1955. The surrogate mother is the legal mother (and any partner is the other legal parent) until an adoption order is made. The surrogate (birth mother) must not give consent to adoption until at least 10 days after the child's birth, in accord with the Adoption Act 1955.

Surrogate adoption is different to traditional adoption (where the birth mother is always the genetic mother, where the pregnancy is accidental. Research into surrogacy in Aotearoa New Zealand, talking to both surrogates and intending parents, discussing their thoughts and experiences with this 10 day legal wait, the actual practise, and their preferences, would be essential research to help inform legal decision making. If the Adoption Act 1955 does go under review, having this research to assist informed legal decision making would be invaluable.

Question 14: Any other comments

Do you have any other comments about the proposals in this document?

Comment 1.

The implication within #160 (Question 12) ("one of the gamete providers would be a parent of any child born from use of the embryo") is that genetic connection is sufficient for "informed consent". Yet Question 19 is proposing to regulate aspects of social parenting. This Consultation is proposing to remove the necessity of biological connection, yet is seemingly still privileging genetic connection over social connection, and therefore requiring social connection to be scrutinised and genetic connection not to be. There are differences between social and medical infertility and it is not clear in this Consultation that there is recognition of these two types of infertility and how they may, or may not, be treated differently.

Differences between social and medical infertility include:

a) children from same-sex parent families know there has been gamete donation. Children from heterosexual parent families will not know, and the heterosexual families have much more of a challenge and responsibility to convey this knowledge to their children. In this respect concerns in *3.1.4 Children Have Interests To Be Protected* are less relevant to the children of same-sex partners.
b) the attitudes of the parents themselves are probably different. Most heterosexuals grow up with the expectation they will be genetically related to their child and, in the case of women, be pregnant and give birth. Lesbians, gay men, and others know they will need eggs or sperm to create their families. Fertility clinics are often a space of failure for straight men and women, but for lesbians, gay men and others, fertility clinics are spaces of opportunity.

Comment 2.

Further to my comments under Question 7.

2) Clarification of "families". Can I please request explicit clarification of what ACART means by "two families" (and by extension, what is meant by "five families", i.e. donors may donate to "five families").

Here are some scenarios highlighting some differences depending on whether the definition is five families or five women:

Sperm donated to five families =

Family 1) lesbian couple A partner and partner two (both using sperm)
Family 2) lesbian couple B partner one has children and partner two (both using sperm)
Family 3) straight couple IVF. They then donate extra embryos to family 4
Family 4) straight couple IVF using donated embryo from family 3
Family 5) single woman

Sperm donated to five women =

Woman 1) lesbian couple A partner one
Woman 2) lesbian couple A partner two
Woman 3) lesbian couple B partner one
Woman 4) lesbian couple B partner two
Woman 5) straight couple IVF. They have extra embryos to donate, but can't because five women have used the sperm.

Sperm donated to five women =

Woman 1) straight couple IVF. They then donate extra embryos to woman 2
Woman 2) straight couple IVF, using donated embryo from woman 1
Woman 3) lesbian couple A, partner one
Woman 4) lesbian couple A, partner two
Woman 5) lesbian couple B, partner one. Partner two cannot use the sperm because five women have used the sperm

Comment 3.
Gamete donation/surrogacy and adoption are very different things.

Adoption is mentioned several times in this Consultation, sometimes aligning with assisted reproduction (#56 "as with adoption"), and sometimes distinguishing them (#57 "While adoption is intended to meet the needs of an existing child, assisted reproduction may involve deliberately creating a child who will have no genetic link to one or both parents (in the case of a couple), and who may also have no gestational link to an intending mother").

#58 - #64 discusses the complexity of this, focusing on embryo donation, which again is different to using either donor sperm or donor eggs.

Minimal research has been done in Aotearoa New Zealand, and research is vital to inform decision making.

In the meantime associating outcomes of adoption with outcomes of gamete donation and surrogacy seems risky. Traditionally adopted children (i.e. not those adopted through surrogacy) may have an additional need to know their origins due to the fact they were separated from their birth family and being an unexpected pregnancy. Gamete donated children however, are born into their families. There is no need to search out the reason why they were placed with another family. For these children their search for genetic origin has a much happier starting place – they are searching for the person who allowed their family to be. While adoptive children may struggle with who their 'real parents' are, this is not the case for gamete donation children. Their parents are who raised them. They may choose to include their donors as family AS WELL, but never instead of their other parents, and this is a huge distinction. Unfortunately research in this area of how children from gametes view their donors is minimal and again would be valuable research to inform decision making.

Comment 4.
Presumably there were processes undertaken to give approval for fertility clinics to use donor eggs and donor sperms to create donor embryos.

Has there been similar discussions around importing sperm (seemingly a less complicated and less ethically complex solution to some infertility) into Aotearoa New Zealand to manage the lack of sperm available in fertility clinics?
#80 outlines rationale for rescinding the biological link policy.

> In addition, rescinding the biological link policy may encourage some people, who are currently excluded from fertility treatment in New Zealand, to remain in this country for their treatment. Treatment in New Zealand, as noted in ACART's 2015 *Import/Export Advice,* offers the following advantages.
>
> - The HART Act's provisions protect intending parents and resulting children.
> - The intending parents can remain close to family and friend support networks.
> - The intending parents do not incur overseas travel costs.

These advantages are true also for women seeking sperm (and single women and female couples are the main clients of fertility clinics). Also, crucially, importing sperm could also reduce risk.

Because of the lack of sperm availability in fertility clinics women source sperm elsewhere. Women travel overseas to access sperm. They are also encouraged by professionals in fertility and maternity services to put themselves in risky situations (more than one lesbian couple has been asked why they don't get pregnant by going down to the pub). They also find themselves in potentially risky situations when seeking sperm (some responses to adverts are described as "creepy" and some potential donors specify sex as a requirement). Women recognised that desperation sometimes meant they were going with what was available, rather than what was right.

Having more sperm available in fertility clinics will ensure more children and parents are being protected by the HART Act's provisions.