

Annex 1 – Slides presented during the EJP RD Executive Committee meeting

06/07/2021

AWP Y4 budget

COORDINATION, TRANSVERSAL ACTIVITIES & COMMUNICATION



Pillar 0

WP1 Coordination and management

Task 1.1 IRDiRC Secretariat

Transfer from unused ODC IRDiRC meetings to PC for IRDiRC Secretariat.

Starting September 2021

28PM 140,000€

Task 1.3 Monitoring of the EJP RD activities and achievements

Remaining budget PC from 51.ULIV transferred to 27.CVBF

TO BE confirmed with ULIV

Additional need

27.CVBF 4PM = 20,000€

(2PM/year)

WP3 Sustainability strategy and business plan

Remaining budget from 1. INSERM RADICO as leader to be transferred 81,900€ to the other participants.

TO BE DESCRIBED



Pillar 0

WP4 Ethical, regulatory, legal and IPR framework of the EJPRD

Additional need:

24.FGB (AREB) 9 PM = 45,000€.

WP5 Communication & dissemination

Budget transfer from WP5 Communication budget to 75.EATRIS WP19 for the Innovation Management Toolbox. 10,000€

Time for discussion





FUNDING OPPORTUNITIES



Pillar 1

WP6 Joint Transnational Calls for collaborative research projects

P1 unused budget:

Additional 1 PM to former call secretariat partners: 24,700€

Additional call (secretariat **to be defined**)

- Call secretariat (PM) 9PM 70,000€
- Evaluation meetings (ODC) 70,000€
- X Funding agency 0,75PM 90,000€

Addition of a WP leader (11. ANR) 2.5 PM : 12,500€

WP8 Rare Disease Research Challenges

12.FFRD use of unspent budget meeting costs to cover consultancy of law office (initially not planned) about 16k€ (12/2020-2021)
Internal FFRD reallocation from ODC to personnel costs.

Time for discussion



TRAINING & EDUCATION



Pillar 3

WP14 Training on data management & quality – discussions still ongoing

Task 14.1

Unused Orphanet PC transfer to ODC:

- graphic designer (3,360€)
- Travel for trainers (20€/trainer)

Task 14.2

Transfer from ACURARE unused ODC to:

- EKUT 1,753€
- ACURARE 1,400€ into PC
- KULeuven 6,750€ into PC

Transfer of unused KULeuven ODC into PC (2,486€)

Due to different % of reimbursement between costs category, these amounts can be revised to match the EU contribution planned.

WP15 Capacity building and training of patients and researchers in Rare Disease research and processes

Updated budget for year 4 and year 5 based on unused budget.

Task 15.3

Transfer from 77.EURORDIS to 26.ISS :

Travel+accommodation: 7,620€

Transfer from 82.ACURARE to 39.MUG

Travel+accommodation: 16,820€

Other (catering): 5,187€

Transfer from 77.EURORDIS to 39.MUG

Travel+accommodation: 7,805€

Other (catering): 450€

WP17 ERN RD training and support programme

Internal change of budget category:

- 65. RadboudUMC transfer its remaining PC 90,228€ into Other direct costs
- 57. UKL-HD transfer 90,228€ from Other direct costs into Personnel costs

Time for discussion



ACCELERATED TRANSLATION OF RESEARCH RESULTS & CLINICAL TRIALS

WP20 Accelerating the validation, use and development of innovative methodologies tailored for clinical trials in RDs – discussions still ongoing

- Addition of 25.FTELE as participant to WP20 and transfer of PC from 61.IOR to 25.FTELE (amount to be described)
- 908k€ are allocated to the selected Innovation projects

Use of remaining budget for:

- Addition of Mini symposium for the Demonstration and Innovation projects: 108,860€ (4 symposium with 35 people)
- Addition of 6PM (36,000€) to 16.UKA for Intermediate course
- Addition of 12PM (72,000€) to 74.ECRIN for the work on the Toolbox and MOOC.

Time for discussion



VIRTUAL PLATFORM OF DATA, TOOLS & RESOURCES

Pillar 2

P2 workshop costs - all partners with workshop budget included: 80,611€ to be reallocated.

WP13 workshops Data provision by ERNs: 50,000€ to be reallocated.

Partners transferring budget need to be identified

In total, the proposition is to reallocate: **130,611€** from P2 workshop costs and WP13 workshop costs on Data provision by ERNs.

WP11 Common virtual platform for discoverable data and resources for RD research

WP12 Enabling sustainable FAIRness and Federation at the record level for RD data, patients and samples

CENTRAL BUDGET - WP12 Fairification costs

- Use of 11,995€ of the unspent budget to cover WP12 Fairification steward activities Y4 & Y5.

Pillar 2 remaining budget estimated at **118,616€**
Will be transferred to Central budget to be used for :

- ERN-VP collaborations
- Y5 Workshops?

WP13 Enabling multidisciplinary, holistic approaches for rare disease diagnostics and therapeutics

Remaining 26. ISS PC budget to be transferred to (54,766€):

- 1. INSERM/AMU
- 36. UM

TO BE DESCRIBED

Time for discussion



Next actions?

- **PLEASE send us the description that are missing for the budget transfers (WP3, P2 workshop costs, WP13, WP14, WP20):**
 - **Who is transferring, how much, to who, why ?**
 - **Final deadline: 15th July**
- Inclusion in the annual work plan year 4
- Final presentation to the GA
- Vote
- Application in the individual budgets

Any question on the process?

Discussion on the extension of the EJP RD

(Administrative constraints to take into account;
risks of non-extension; how long; which activities)

Year 6 Extension Context

Only ONE request for extension is possible if approved.

It is not possible to first request an extension of 6 months and later request another project extension.

Only activities initially planned in the Grant agreement, description of the action, requiring extension will be accepted. Only funded projects and their support activities will be accepted for extension.

6 months extension

Easy to get especially for Cofund actions (with funding activities)

12 months extension

Further justification requested

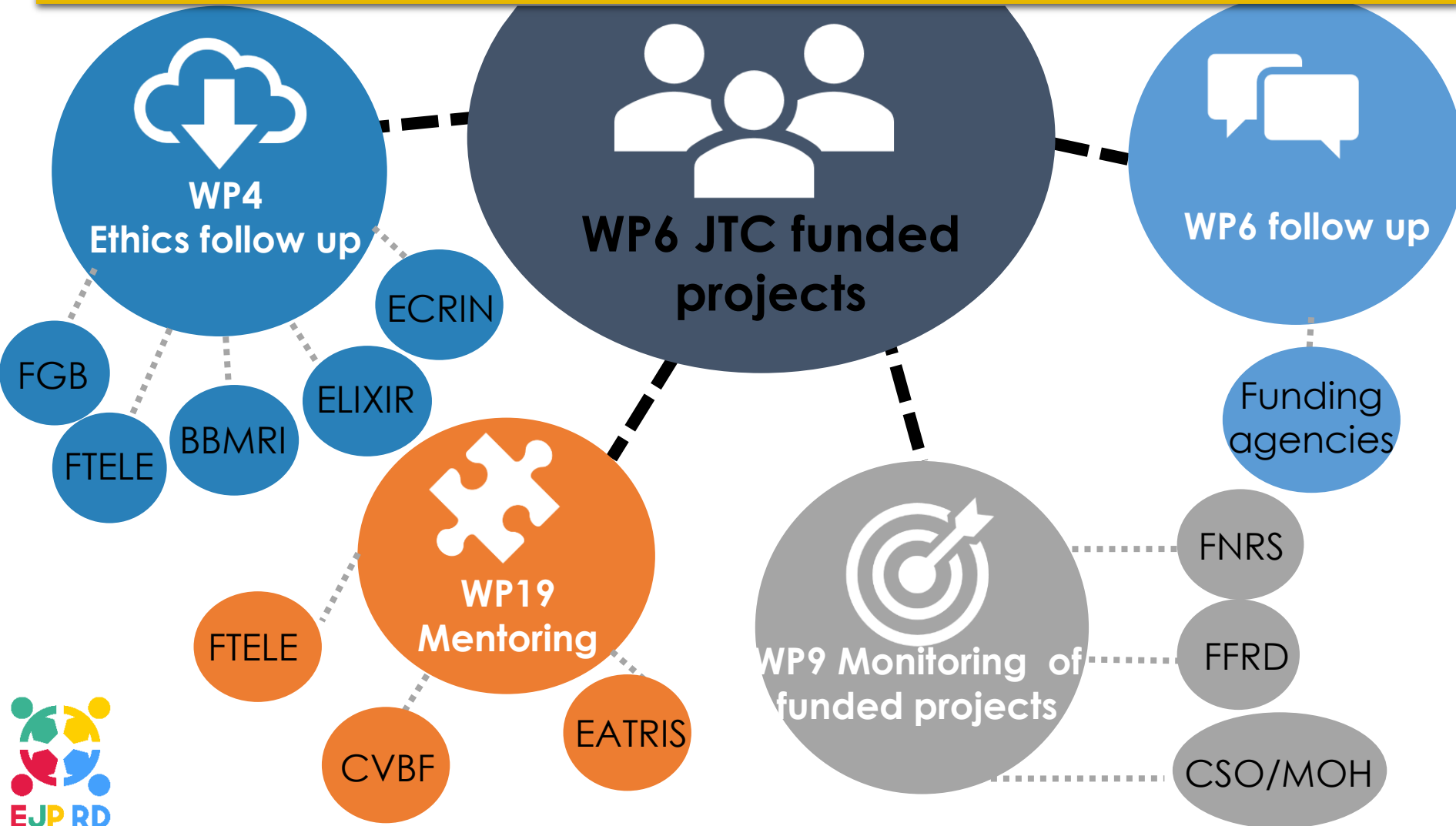
Additional deliverables requested

Need to be reviewed and approved by the HADEA Director

Due to covid-19, HADEA agency under many amendment requests. PO advise to wait before requesting the amendment extension.

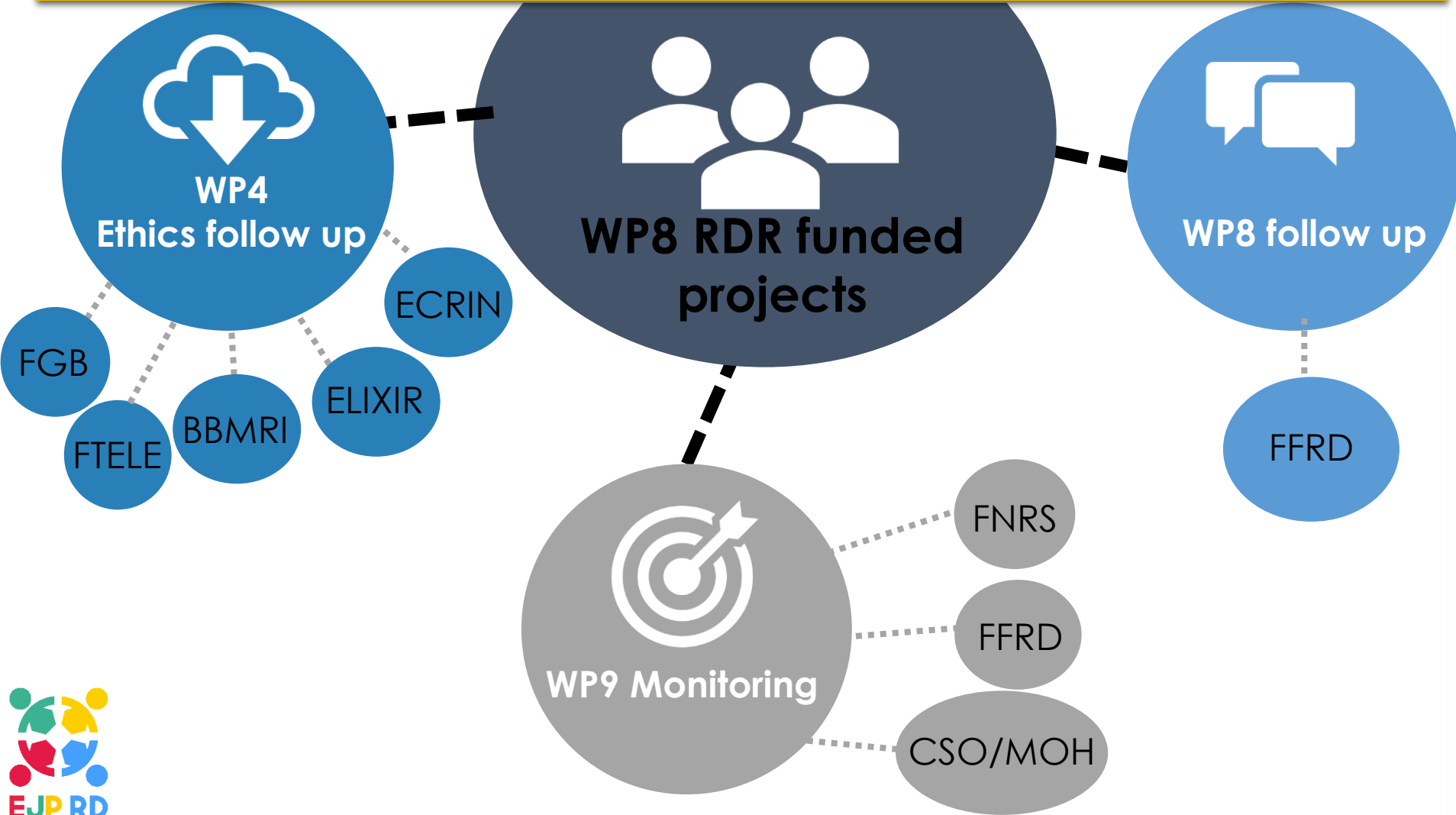
Year 6 activities

Coordination, Transversal activities & communication



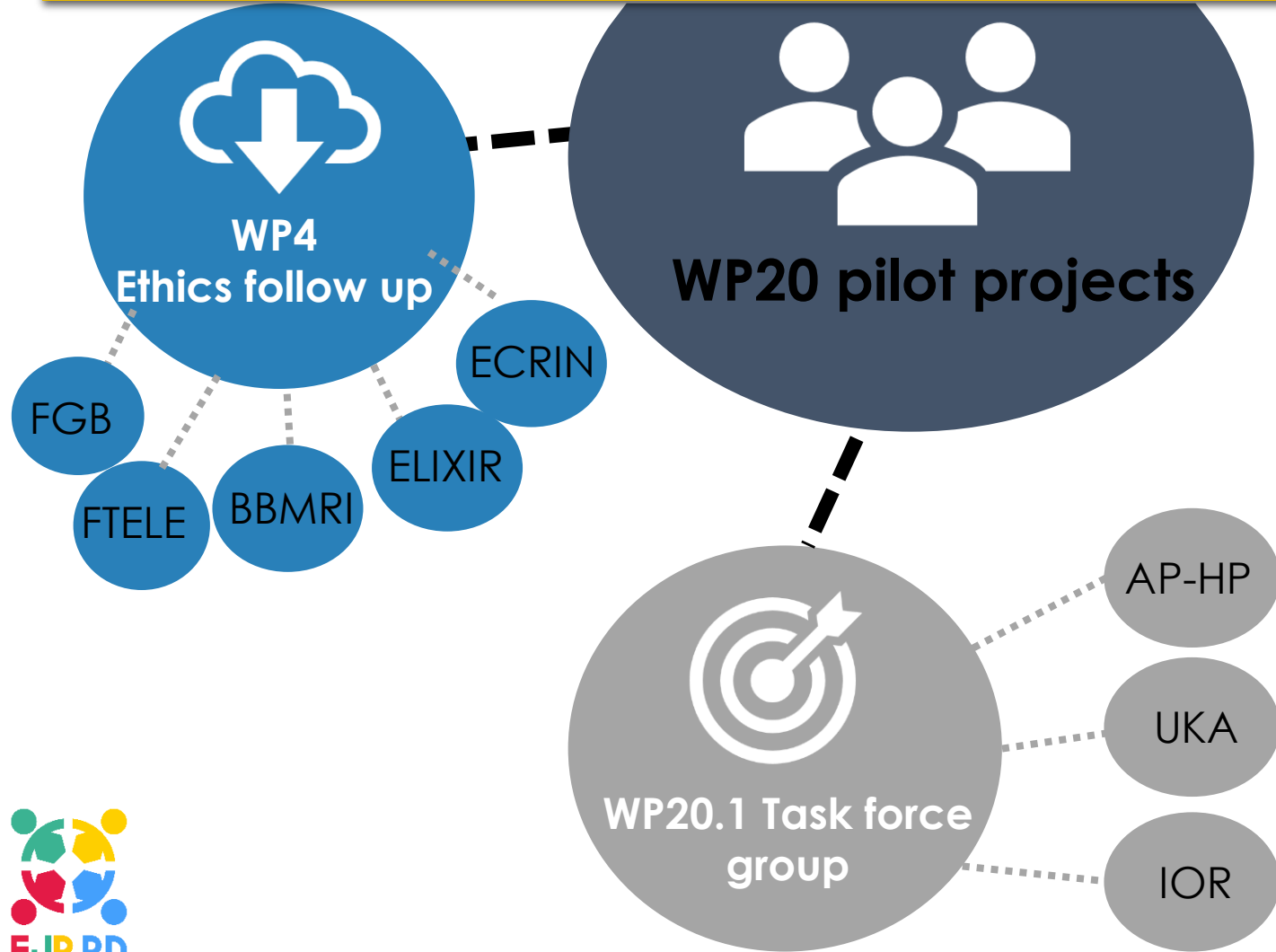
Year 6 activities

Coordination, Transversal activities & communication



Year 6 activities

Coordination, Transversal activities & communication



Year 6 Extension estimation of personnel costs (ONE year)

	PM	Direct Costs	Indirect costs	EU Contribution
Coordination	44.00	254 500	63 625	318 125
Operating group	9.80	71 138	17 785	88 923
WP1.3 Monitoring EJP RD activities	6.00	48 000	12 000	60 000
WP4 Ethical, regulatory, legal and IPR framework of the EJP RD	9.00	44 964	11 241	56 206
WP6 Joint Transnational Calls for collaborative research projects	18.20	107 457	26 864	134 321
WP8 Rare Disease Research Challenges	3.40	25 500	6 375	31 875
WP9 Monitoring of funded projects	5.00	32 300	8 075	40 375
WP19 Facilitating partnerships and accelerating translation for higher patient impact	8.90	56 500	14 125	49 438
WP20.1 Task force group	7.80	46 800	11 700	40 950
TOTAL	112.10	687 159	171 790	820 212

Expected unused budget based on internal reallocations

	Unused costs	Planned use Y4-Y5	Additional needs	Direct costs remaining	Total costs remaining (with indirect costs)	EU Contribution
P0	241,841	241,841	65,000	-65,000	-81,250	-81,250
P1	599,774	267,200		332,574	415,718	415,718
P2	130,661	130,661		0	0	0
P3	378,200	378,200	25,000	0	0	0
P4 projects	2,060,467	216,860		1,843,607	2,304,509	1,613,156
Total	3,410,943	1,234,762	65,000	2,111,181	2,638,976	1,947,624



Thank you